AFRICAN REGIONAL MEETING ON PILOT PROJECTS

FOR THE PREVENTION

OF MOTHER-TO-CHILD TRANSMISSION OF HIV

GABORONE, BOTSWANA MARCH 27-31, 2000

UNICEF/UNAIDS/WHO/UNFPA









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ACRONYMS

ACRONTINIS	T
3TC	Lamuvidine
ACTG	Aids clinical trials group
ANC	Antenatal care
ARM	Artificial rupture of membranes
ARV	Antiretroviral
AZT	Zidovudine (also ZDV)
BFHI	Baby friendly hospital initiative
BMS	Breast milk substitute
CBO	Community-based organisation
CPA	Country programme advisers
EPI	Expanded programme on immunisation
HIS	Health information system
IATT	Inter-agency task team
IEC	Information, education and communication
IMCI	Integrated management of childhood illness
IPAA	International partnership against AIDS in Africa
M &E	Monitoring and evaluation
MCH	Mother-child health
МОН	Ministry of Health
MSF	Medecin sans Frontiere
MTCT	Mother-to-child transmission
NGO	Non-governmental organization
NNRTI	Non-nucleoside reverse transcriptase inhibitor
NVP	Nevirapine
OI	Opportunistic infection
PCR	Polymerase chain reaction
PETRA	Perinatal transmission study
PLWH/As	People living with HIV/AIDS
PMTCT	Prevention of mother-to-child transmission
ROM	Rupture of membranes
RT	Reverse transcriptase
RWG	Regional working group
SADC	Southern Africa development community
SMI	Safe motherhood initiative
STD	Sexually transmitted disease
STI	Sexually transmitted infection
TB	Tuberculosis
VCT	Voluntary counselling and testing
ZDV	Zidovudine
L	

INTRODUCTION

The HIV/AIDS epidemic is resulting in more than 600,000 infants becoming infected each year, and in many countries HIV/AIDS has become a major cause of infant and young child mortality. From a human rights perspective, governments and UN agencies have an obligation to support action to prevent infants from becoming infected.

Since the initiative for the prevention of mother-to-child transmission of HIV (PMTCT) was launched in 1998, it has become clear from the increasing scientific evidence and recent results from countries such as Botswana, Cote d'Ivoire, Uganda, Rwanda and Zimbabwe, that it is possible to make a difference.

At country level, more national leaders and governments are recognising the seriousness of the situation and are creating a supportive political environment by setting up national HIV/AIDS councils and secretariats and committing government resources to the response to HIV/AIDS. Within the framework of the International Partnership against HIV/AIDS in Africa (IPAA), a number of international agencies (UNICEF, WHO, UNFPA) under the coordination of UNAIDS, have already demonstrated their commitment to supporting interventions aimed at preventing mother-to-child transmission (MTCT) in Africa. Some countries are moving from pilot projects to scaling-up.

The current actions, however, are clearly not enough. There is an urgent need for more countries to start implementing PMTCT interventions on a national scale in order to have a meaningful impact. In addition, the planning and implementation of PMTCT interventions should be broadened to increase participation and support for HIV-infected women, and encourage greater involvement of males and people living with HIV/AIDS. Primary prevention of HIV infection in women of reproductive age should remain the focus of interventions to reduce MTCT of HIV. Early identification of HIV-infected women of reproductive age through improving accessibility and acceptability of voluntary counselling and testing (VCT) services and appropriate counselling on reproductive options should also be given due consideration in the context of PMTCT strategies.

In short, a much more substantial response to PMTCT of HIV is urgently needed from all actors – governments, non-governmental organisations (NGOs), local communities, the private sector and international development organisations.

In light of the above, participants from 14 countries in Africa, Latin America and the Caribbean representing government and NGOs met in Gaborone, Botswana, from 27-31 March 2000 with the specific objectives of taking stock of the present status of implementation of interventions for the prevention of MTCT of HIV and proposing appropriate corresponding actions. The list of participants is attached in Annex 1.

OBJECTIVES AND EXPECTED OUTCOMES OF MEETING

The objectives of the meeting were:

- to share experiences and lessons learned in the PMTCT pilot projects;
- to identify the major challenges encountered in the pilots and attempt to address them;
- to strengthen key components of projects on selected issues, e.g. communication, VCT, infant feeding, selection of tests and drugs, care and support for HIV-infected women and their children;
- to strengthen and coordinate monitoring and evaluation, and plan for documentation of the pilot projects in order to stimulate adaptation in other settings;
- to identify further needs for technical support, networking and guidelines;
- to explore how to scale-up the projects within pilot countries and how to initiate implementation in other countries.

The expected outputs included:

- participants to be briefed on progress in PMTCT pilot projects;
- project presentations, especially the report of the evaluation of the Botswana pilot project, to be compiled for documentation of PMTCT pilot project Best Practices collection;
- major problems in pilot projects to be identified, discussed and solutions proposed;
- key project components to be strengthened, based on shared experiences and technical input;
- plans to be strengthened for project monitoring, evaluation and documentation of pilot projects;
- plans to be developed for future technical assistance, regional networking and guidelines;
- timelines to be developed for scaling up within pilot countries and other countries.

METHODS OF WORK

Several different methods were employed during the meeting: presentations of technical updates and documents, presentations of country experiences followed by discussions, group discussions on key issues, a field visit to PMTCT pilot sites in Gaborone, and country-specific group work on monitoring and evaluation plans. To summarise by day:

Day 1:

After the official opening, technical updates were presented on drugs and infant feeding, followed by discussion. Countries were then requested to share experiences, concentrating on a specific topic, with discussions at the end of the session. In the last session of the day, recently developed materials, guidelines and training courses were briefly introduced.

Day 2:

During the second day, group discussions on priority topics highlighted lessons learned in the pilots in the areas of communication, VCT, infant feeding, care and support, antiretroviral (ARV) drugs and HIV tests.

Day 3:

In the morning, participants split up into groups and visited health facilities in Gaborone. The afternoon was spent in three groups, further discussing communication, VCT and infant feeding, referring to the observations in the field.

Day 4:

This day was entirely devoted to monitoring and evaluation, with presentations of country experiences and monitoring and evaluation (M&E) documents, country-specific group work on M&E plans and presentations from selected countries.

Day 5:

The last day looked at the way forward, scaling up and resource mobilisation in the framework of the IPAA. Countries listed their needs for support, and representatives of UN agencies at regional and global level discussed how coordination of support could be improved. In the final session, the participants agreed upon the conclusions and recommendations from the meeting.

SESSION 1: OPENING

This session was chaired by M. Chikalisa, Permanent Secretary, Ministry of Health, Botswana.

Self-introduction

Participants were first asked to introduce themselves.

Address on behalf of UNICEF

David Alnwick, Head of Health Section at UNICEF New York Headquarters, welcomed participants on behalf of UNICEF. He pointed out that the HIV pandemic has been increasingly recognised as an emergency. While in the 1980s and early 1990s the response was mainly health-sector based, in recent years AIDS has become everyone's concern, and the emphasis has moved towards a multi-sectoral approach.

UNICEF has identified five priorities in its HIV/AIDS programme: (1) Awareness creation, (2) Primary prevention, focusing on young people, (3) Secondary prevention (including PMTCT), (4) Care for orphans, and (5) Establishing standards for staff care.

Paediatric AIDS has increased the burden on children and their families and on the health services, and so PMTCT is a priority regionally and globally. The gap between what can be done and what is being done in developing countries is very wide. Improved access to effective interventions through antenatal care (ANC) and other routine health care services should increase awareness of HIV, accelerate acceptance of VCT and help to break the silence surrounding HIV/AIDS. Implementation of PMTCT should go hand-in-hand with implementation of other services. We cannot wait until all other services are in place, but should build on what is already working on the ground.

UNICEF sees AIDS not as another vertical programme, but as its core business. UNICEF intends to increase the allocation of funds for HIV/AIDS in general, including PMTCT. UNICEF is also committed to increasing the supply of test kits, training materials and ARVs.

Address on Behalf of the Botswana UN Theme Group on HIV/AIDS

The Botswana Chair of the UN Theme Group on HIV/AIDS and WHO Country Representative, Teguest Guerma, pointed out that the objective of the workshop is to share experiences from different countries on interventions in place to reduce the death of children due to HIV/AIDS. In developing countries, MTCT is the leading cause of HIV-infection in children. Of the 3 million infants infected with HIV, 90% are in Africa. MTCT has contributed to an increase in the infant mortality rate.

Cheap ARV drug regimens are now available for the prevention of MTCT. However, a programme for prevention also requires strong VCT, ANC, delivery care, postnatal care and infant feeding programmes which are often non-existent in developing countries; this remains a major challenge.

In sub-Saharan Africa most HIV-infected women continue to breastfeed in spite of the transmission risk to their infant. This practice is based on both economic necessity and also the fear of stigmatisation that may follow if women adopt an alternate feeding practice which may disclose her status. The Durban study on exclusive breastfeeding has caused confusion; this study observed different transmission rates with different types of breastfeeding practice.

The PMTCT programme should go hand-in-hand with adolescent programmes to ensure that children remain HIV-negative all their lives. There is a need, therefore, to strengthen primary prevention programmes. UNAIDS cosponsors are committed to supporting the PMTCT of HIV.

Opening Address on Behalf of the Government of Botswana

The Minister of Health of Botswana, Hon. J. Phumaphi, opened the meeting officially. She began by stating that 10% of HIV infections worldwide are in children and because of high infection rates and high fertility rates 90% of these are in Sub-Saharan Africa. HIV has devastating social and economic consequences.

Botswana's PMTCT programme started with the establishment of a Task group in 1998; UNICEF committed itself as one of the main partners in PMTCT. Although PMTCT interventions are now offered in most of the health units in Gaborone and Francistown, uptake of PMTCT is still very low.

Regional cooperation in PMTCT is critical to its success. There is a need for intensified, well-targeted implementation in the African region. The interventions should be monitored to demonstrate whether a reduction of transmission from mother-to-child is being achieved in countries implementing PMTCT programmes, and at what pace? There are, however, a number of questions that need to be answered; for example, how many lives should be lost before expanding? Can community-based ARV therapy be made available to HIV-infected women after delivery in order for them to care for their children?

There is a need, now, to move away from the pilot phase and scale up the interventions. We will not have succeeded until each mother has access to PMTCT services. We do not have time to wait! By next year, there should be fewer pilots and more interventions on a larger scale.

Strategies need to be developed to ensure that children are brought up in a caring environment and can later contribute economically to society. All must work together since time is not on our side!

SESSION 2: TECHNICAL UPDATES

Update on Drug Treatment for PMTCT

James McIntyre, UNICEF consultant, presented updated information on the various studies, that have been or are being carried out, on the use of ARVs in PMTCT. Some recent findings and concerns were reported:

ZIDOVUDINE (AZT or ZDV)

- ♦ Findings:
 - > more results are becoming available from the short course AZT studies
 - > longer-term follow-up is confirming the increase of postnatal transmission with breastfeeding
 - reduction in viral load has been shown to be correlated with reduced peripartum transmission risk

♦ Studies:

1) ANRS 049a: short-course AZT in a breast-feeding population.

Placebo-controlled study

Mothers were given: oral AZT 300 mg BID starting at 36–38 weeks of pregnancy

+600 mg in labour

+ for one week post-natally

Children were predominantly breastfed

Results: transmission reduced by 35% at 180 days; reduced by 30% at 450 days [Dabis, et al., 6th Conference on Retroviruses and Opportunistic Infections, Chicago, 1999]

2) Thailand: ongoing perinatal HIV prevention trial.

Non-breastfeeding population

Factorial design (long-long; short-short; short-long; long-short)

Mothers were given: oral AZT 300mg BID starting at 28 weeks or 36 weeks

No post-natal dose

Children were given: 2mg/kg QID for 3 days or 6 weeks

Remark: Short-short was stopped because of higher transmission rates (10% in short-short)

Resistance:

Conflicting results are reported on the development of resistance in women receiving AZT in pregnancy.

- analysis of the ACTG 076 study showed low-level AZT resistance in 0.3%-6.8% at baseline (95% confidence intervals) and 0.3%-14% for delivery incidence. No high level resistance (215 mutation) was seen, and there was no increase in transmission rate. [J Infect Dis, 1998; 178:557-64]
- the Swiss HIV and Pregnancy Study prospectively evaluated 62 women receiving the ACTG 076 regimen. Six women (9.6%) harboured a T215Y/F mutation, which is associated with high-level resistance to AZT. None of the children of these women were infected. [J Infect Dis, Mar 99; 179: 705-8]
- resistance associated with a higher transmission rate was reported in one new study. Of 142 women in Minnesota receiving AZT in pregnancy, 5% had at least one AZT-associated resistance mutation at delivery. The presence of any reverse transcriptase (RT) mutation resulted in an odds ratio of 5.16 for perinatal transmission. [AIDS 263-271]

➤ PETRA Study (UNAIDS)

This is a placebo-controlled trial with 4 arms:

	Antepartum	Intrapartum	Postpartum
A	AZT + 3TC	AZT + 3TC	AZT + 3TC
В	Placebo	AZT + 3TC	AZT + 3TC
C	Placebo	AZT + 3TC	Placebo
D	Placebo	Placebo	Placebo

There were 5 sites in: South Africa, Uganda and Tanzania.

Interim results are available for 1,326 infants at 6 weeks of age (breastfeeding populations):

Regimens	N=	Children	Transmission	Relative risk	(95% CI)	P value
		infected	rate %			
Arm A	359	31	8.6	0.50	(0.33-0.77)	0.001
Arm B	343	37	10.8	0.63	(0.42 - 0.94)	0.02
Arm C	351	62	17.7	1.03	(0.73-1.45)	NS
Placebo	273	47	17.2	1.0		
All	1,326	177	13.3	0.61	(0.42 - 0.89)	

Resistance:

Rapid development of resistance to lamivudine (3TC) when combined with AZT in pregnancy (Clarke et al 1999)

Results available on 19 women, receiving AZT or AZT/3TC in 2nd or 3rd trimester. 2 out of 10 women tested had genotypic mutations associated with decreased susceptibility to AZT at delivery. 4 out of 5 women in the dual therapy arm had the M184V mutation in the RT gene associated with decreased susceptibility to lamivudine at delivery.

Mitochondrial toxicity

French study (Blanche et al 1999).

Cohort of around two hundred infants whose mothers had received nucleoside analogues

8 children had mitochondrial dysfunction (all uninfected)

5 (of whom 2 died) presented with delayed neurological symptoms

3 were symptom-free but had severe biological or neurological abnormalities

4 had been exposed to combined AZT

US retrospective investigation.

15,229 children whose mothers had received ARVs in pregnancy, in whom there were 216 deaths No deaths strongly suggestive of, or proven to be due to mitochondrial dysfunction 37 deaths included 'possible' mitochondrial dysfunction in the list of differential diagnosis; all of these were in HIV-infected children with clinical evidence of HIV-related diagnoses at death

NEVIRAPINE (NVP)

Properties:

- non-nucleoside reverse transcriptase inhibitor (NNRTI)
- potent inhibitor of HIV-1 reverse transcriptase
- rapid absorption
- good crossing of the placenta
- long half-life
- highly lipophilic
- wide distribution throughout the body

Studies/trials:

- > Studies in chimpanzees have shown a prophylactic effect of NVP in preventing HIV-1 infection
- HIVNET 012: A phase IIB randomised, controlled trial to evaluate the safety, tolerance, and MTCT rate associated with short course NVP vs. very short course AZT in HIV-infected pregnant women and their infants in Uganda.

Placebo arm dropped in February 1998: continued as NVP vs. AZT intrapartum and postpartum Analysis of HIV status of children at 6-8 weeks and 14-16 weeks

Similar incidence of side effects in AZT and NVP groups

Ongoing SAINT (South Africa Intrapartum Nevirapine Trial) study:

Multi-centre study

Mother: NVP in labour plus one dose postpartum

Infant: NVP one dose within 48 hours

Compared to PETRA Arm B

1200 mother-infant pairs

Results to be presented at Durban 2000

- NVP added to WHO Essential Drug List in December 1999 for indication of MTCT
- Registration for MTCT recommended by Clinical Committee of South African MCC: not yet confirmed by full Council
- > Introduced into pilot project in Kampala
- Elizabeth Glaser Pediatric AIDS Foundation: 8 funded projects with NVP to start soon

Resistance:

- > Data from HIVNET 006: Kampala
- > Plasma specimens collected at 6 weeks after single dose NVP to women in labour
- > 14 specimens tested
- > K103N primary NVP resistance mutation detected in:

1/3 transmitters

2/11 non-transmitters

Pre-dose specimens available for 2 of these 3: no K103N found

COMPARISON OF MTCT DRUG REGIMENS (at 6 weeks):

	Active arm	Placebo	% reduction	P value	Breastfeeding
ACTG 076	8.3%	25.5%	67	0.00006	0%
Thailand	9.4 %	18.9%	51	0.008	0%
ANRS 049a	17.8%	25.8%	31	0.108	100%
PETRA A	8.6%	17.2%	50	0.001	69%
PETRA B	10.8%	17.2%	37	0.02	67%
HIVNET 012	11.9%	21.3%	50	0.0027	95%

COMBINATION TREATMENTS

- > Transmission rates of below 5% reported in women receiving highly active combination treatments
- An increased rate of pre-term delivery was reported in a retrospective Swiss study of 30 HIV-infected pregnant women receiving combination antiretroviral therapy with and without protease inhibitors
- In a larger study of 462 HIV-infected pregnant women delivering between 1998 and 1999 in clinical trial sites in the US, the incidence of pre-term delivery and low birth weight did not differ by type of maternal antiretroviral therapy

OTHER DRUGS AND COMBINATIONS UNDER STUDY

- ➤ Short course AZT plus intrapartum NVP: Cote d'Ivoire
- ddi / d4T / ddi+d4T / AZT from 36 weeks: Phase II study in progress in Soweto: Results to be presented at Durban conference
- Emivirine (MKC-442): Phase I study completed: May move to phase II

NEW DIRECTIONS

- Antiretroviral treatment to breastfed infants:
 - HIVNET 023 and other studies
 - May be limited by development of resistance
- NVP resistance data may make it necessary to consider innovative combination regimens

WHO Technical Consultation on Use of Nevirapine in PMTCT

Dirk Buyse of WHO Geneva gave a short report on the technical consultation on use of NVP which took place in Geneva in March 2000.

Participants (18) included:

Consultants (virologists, clinicians and policy advisers) [7]

Investigators [2]

Representatives from Boehringer-Ingelheim [2]

Secretariat (WHO, UNICEF and UNAIDS) [7]

The objectives of the consultation were:

- to review the most recent findings on NVP resistance and their possible implications for MTCT prevention
- to establish what additional information is expected in the near future
- to agree on what additional information is required

Background studies that formed the basis for the consultation:

- "Selection of the K103N Nevirapine resistance mutation in Ugandan women receiving NVP prophylaxis to prevent HIV-1 vertical transmission", G Becker-Pergola, L Guay, F Mmiro, P Musoke, F Sung, JB Jackson and SH Eshleman, 7th Conference on Retroviruses and Opportunistic Infections: Jan 30 Feb 2, 2000
- ♦ HIVNET 006: Ugandan Phase I/II trial

Objectives: To determine the presence of NVP-resistant mutations in treatment-naïve Ugandan women

following a single 200 mg dose of NVP

Methods: HIV RT sequences were analysed from plasma collected from 14 women 6 weeks after NVP

dosing in labour

Results: K103 primary NVP resistance detected in 3 samples. No other NVP-resistant mutations present

in any woman

Conclusion: HIV with the K103N mutation can be selected for when a single dose of NVP is given to Ugandan women. Resistance to NNRTIs may be induced in the setting of NVP prophylaxis

Conclusions:

- Rapid emergence of NVP resistant virus has been previously observed in adults receiving chronic NVP treatment as a single agent.
- Given the pharmacokinetics and the high potency of NVP, selection of resistant virus was not wholly unexpected (even after a single dose).
- It is unlikely that selection of resistant virus occurred in the few hours before delivery.
- It is also unlikely that resistant virus is transmitted during labour or delivery to infants who become infected despite treatment.
- Rapid selection of resistant virus may compromise the efficacy of the NVP dose given to the infant.
- ◆ The likelihood of transmission of resistant virus during breastfeeding is of greater concern.
- NVP may be less effective in reducing the risk of transmission during a subsequent pregnancy.
- Although the infectivity and pathogenicity of selected NVP-resistant variants is unknown, previous studies on other drug-resistant viruses do not suggest that such variants are more transmissible or worsen the prognosis of HIV infection.
- Resistant virus is expected to reach undetectable levels within a few weeks or months after cessation of treatment
- Temporary selection of resistant virus induced by a single dose of NVP during labour is not expected to lead to emergence of NVP-resistant strains in the population.
- Of greater concern is potential emergence of NVP-resistant strains in the population if NVP were used in suboptimal treatment regimens.

Implications for future therapeutic options for women and children with resistant virus:

- The efficacy of combination therapies not including NVP or other NNRTI antiretrovirals should not be altered.
- In theory potent combination therapies, which include NVP or another NNRTI, should not allow reemergence of resistant virus.
- The use of NNRTIs in sub-optimal combinations should be avoided.
- Research studies are needed to assess the impact of previous NVP administration on the effectiveness of subsequent antiretroviral treatment, should such options become available.
- Research is needed to explore options to reduce transmission through breast milk, and potent and affordable long-term combination therapies.

Next steps:

 An updated article on the use of antiretrovirals in MTCT-prevention will appear in the WHO Weekly Epidemiological Record.

A follow-up review is planned by WHO in the second half of 2000

Update on Infant Feeding

Felicity Savage (Department of Child and Adolescent Health, WHO Geneva) summarised recent research on practical aspects of HIV and infant feeding, and their implications for policy.

A recent analysis by WHO of infant mortality found that infants who are not breastfed in the first two months of life have six times the mortality of infants who are breastfed. The dangers of not breastfeeding must be taken into consideration when recommending replacement feeding for children of HIV-infected mothers.

(Ref: WHO Collaborative Study Team, Effect of breastfeeding on infant and child mortality due to infectious diseases in less developed countries: a pooled analysis. Lancet 2000;355:451-55)

Formative research in Zambia suggests that giving replacement feeding to their infants would not be an easy option for HIV-infected mothers. Many mothers find that:

- it is difficult to buy and give formula regularly
- it is difficult to boil water and prepare adequate feeds one by one
- expressing and heat treating breast milk is not easy

The researchers concluded that if replacement feeding is introduced, regular monitoring of feeding practices among HIV-infected women will be needed, and also of 'spillover' among HIV-negative and untested women. It will be essential to train both health workers and community support groups in the management and support of breastfeeding and replacement feeding. They need to be able to help uninfected and untested mothers to breastfeed as recommended; to support HIV-infected mothers who choose to breastfeed to do so exclusively; to help those HIV-infected women who choose replacement feeding to do so adequately and as safely as possible.

A study in Kenya (Nduati R., John G., et al) found that while HIV-free survival was greater among children given replacement feeds, the overall mortality at two years of age was not significantly lower than that of breastfed children, some of whom were HIV-infected. This was in spite of mothers having access to piped water and being provided with formula milk. The investigators found that mastitis and breast abscesses increased HIV transmission associated with breastfeeding. (Ref: John G, Nduati R. et al., Correlates of perinatal HIV-1 transmission in the Kenya breastfeeding study. Abstract 13 et5-1 XI International Conference on AIDS and STDs in Africa, September 1999, Lusaka, Zambia)

A study in Malawi reported that high levels of sodium indicative of sub-clinical mastitis were associated with increased levels of virus in breast milk, and possibly with increased risk of MTCT. (Ref: Semba et al. Human immunodeficiency virus load in breast milk, mastitis and MTCT of HIV₁. Journal of infectious diseases 1999, 180)

Improved breastfeeding technique and frequent removal of breast milk may reduce the prevalence of mastitis and sub-clinical mastitis. Thus, there is a need to strengthen breastfeeding management amongst health workers; to strengthen the Baby Friendly Hospital Initiative (BFHI); to improve breastfeeding counselling to all mothers and particularly to HIV-infected or untested mothers who choose to breastfeed; to prevent 'spillover' of artificial feeding amongst HIV-uninfected and untested mothers. It is also necessary to follow up infants of HIV-infected mothers for a minimum of two years, to prevent malnutrition associated with inadequate/inappropriate replacement and complementary feeds. Policies are needed that address all infant feeding issues in a balanced way – breast and complementary feeding and HIV, and to ensure that mothers are able to make informed choices for their situation.

Discussion

The following points came out during the discussion period:

- 1. Further clarification on mixed feeding and HIV transmission was requested.
 - A study of HIV-infected women in Durban investigating the influence of vitamin A on MTCT observed a significantly higher transmission rate among children who were mixed breastfed compared with those who were exclusively breastfed. By contrast, no significant difference was found between children who were exclusively breastfed and those given formula feeds. More research is necessary to verify these findings.
- 2. What are the benefits of giving AZT syrup to infants born of HIV-infected women for one week postpartum? No reduction in transmission was noted for infants in the Cote d'Ivoire study, so it appears that the one-week regimen for infants was not useful. Other antiretroviral drugs or combinations of drugs are required if short course postnatal interventions are intended.
- 3. Is the Thai regimen adequate?
 - At least two weeks of AZT has been proven to work. Clients need to be monitored, however, to ensure that AZT therapy is taken for more than two weeks where possible.
- 4. How can we manage HIV-infected women presenting in pre-term labour?

 NVP can be given to the mother in labour, and either a single dose of NVP or 6 weeks of AZT to the baby.
- 5. Do the drugs (AZT/NVP) themselves cause resistance?
 - The drugs select the viruses with resistance, and these proliferate. Once the drug is removed other wild viruses come up.
- 6. There is a contradiction in asking countries to go to scale, while at the same time discouraging use of NVP on a wide scale.
 - WHO decided in consultation that NVP can be used as an alternative option in pilot programmes for PMTCT until more clinical information is provided. There is, however, inadequate information on the long-term effects of ARVs and hence, it was agreed that WHO should provide guidelines rather than leaving countries to decide for themselves.

SESSION 3: SHARING OF COUNTRY EXPERIENCES

During this session, each country represented was asked to give a presentation on a particular aspect of their PMTCT project, either from the perspective of their experience in implementation, or of their plans to get started.

Zambia

Zambia presented its experience in developing a communication strategy. The purpose of the strategy is to create awareness and increase knowledge on HIV/AIDS at all levels, through the provision of accurate information with specific emphasis on MTCT in order to reduce stigma and ensure acceptability.

Their approach includes to:

- carry out formative research to inform the strategy
- carry out information, education and communication (IEC) activities to influence behaviour and attitudes
- advocate at various levels to influence policies, programmes, strategies and legislation
- train health workers in communication and counselling skills
- train community peer educators

The findings from the formative research to date include:

- a high level of stigma against HIV/AIDS patients exists. The community tends to shun persons who are known to be HIV-infected or have symptoms of AIDS. The local names for HIV/AIDS reflect this level of stigma.
- there is limited knowledge about MTCT among the persons interviewed.
- high levels of contact with health facilities exist, with 80% attendance for at least one ANC visit, and 75% of those women delivering at the same health centre.
- most women exclusively breastfeed for two to three months. Some acceptable reasons for not breastfeeding
 were illness in the mother, pregnancy and the mother having to return to work. However, a woman who did
 not breastfeed at all was said to be 'non-caring' and/or 'lazy', 'Westernised and promiscuous'.
- respondents gave good reasons for accessing VCT. Some wanted to know their status in order to plan whether
 to have children while others suspected they may have HIV/AIDS following the death of their spouse or
 partner.
- communities generally know that condoms prevent STDs and HIV transmission. However, men are reluctant to use condoms even in the context of marriage.

Based on the above information, an implementation plan has been set in motion:

- > a communication strategy was developed based on a UNICEF draft regional strategy document, information obtained from a 'Communication' course in Geneva, and the expertise of a local sub-group of the MTCT Task Force.
- > stakeholders were oriented in the basics of the strategy. This included staff from the Ministry of Health, the Central Board of Health, district health management teams and health workers at Chipata Health Centre (one of the sites of the PMTCT pilot project). The community was involved through neighbourhood health committees, mothers' support groups and the Catholic Home-Based Care.
- ➤ IEC messages and materials have been produced including a brochure for men and women of childbearing age, an information booklet for service providers, a care package poster for health workers, an information pamphlet on ARVs for HIV-infected parents, and a drama piece for performance in the community.

So far, the feedback from the community has been positive. They expressed their enthusiasm for the intervention, and that it should start soon. There is some misunderstanding, however, regarding why all ANC mothers are not receiving ARVs. It is recognised that to be successful it is necessary to target messages for males.

Several challenges remain:

- > increasing knowledge on MTCT and increase understanding of the importance of prevention
- > communicating to men and foster male involvement
- > improving access to VCT
- > reducing stigma against mothers who do not breastfeed
- > making condom use acceptable within the context of marriage
- reaching adolescents

The next steps include:

- > production of visual aids for health workers to use when giving health education in ANC
- > continuing contact with community groups
- > dissemination of IEC materials and drama activities
- > initiating community counselling activities

Cote d'Ivoire

Cote d'Ivoire presented its experience of VCT in the two years that there has been activity either in the context of research or during the six-month pilot project. Several collaborating agencies have been involved during this period, including the National AIDS Control Programme (PNLS), French Research Institutes (ANRS/IRD), American Research Institutes (CDC/RETRO-CI), the Therapy Intervention Programmes through the PNLS and the French Government (FSTI – PMTCT/ARV) and UNICEF-Abidjan.

The general HIV/AIDS epidemiological situation in Cote d'Ivoire is described below:

Indicator

HIV sero-prevalence in general population	10%	1998
Sex ratio	4,2	1988
	1,2	1998
HIV sero-prevalence among pregnant women	8-13,8%	1998
MTCT without any ARV intervention	25%	

Reduction of MTCT with short course AZT 38% risk reduction to 18% 1998, 2 studies (ANRS & RETRO-CI)

Various phases of the MTCT programmes have been completed, and are described in the following tables:

Sponsors	Programme	Period	Results over Period	
Ditrame	Research	1995-1998	6 months	
Transition	Intervention	Oct 1998 – March 1999	6 months	
FSTI	Intervention	April 1999 - Dec 1999	9 months	

Services offered	Transport	Medical Care	VCT	Iron-folic acid	AZT	**BMS	ARV Therapy
Ditrame	X	X	X	X	X		
Transition			X	X	X	X	
FSTI		*STD care	X	X	X	X	X

^{*}STD – Sexually transmitted disease **BMS – Breast milk substitute

VCT service	Ditrame		Transition		FSTI	
	Total	Monthly	Total	Monthly	Total	Monthly
ANC, new	5,641	940	4,309	718	11,133	1,237
Tests proposed (TP)	3,938	656	3,756	626	8,737	971
Tests accepted (TA)	3,389	565	3,452	575	5,718	635
TA/TP	86%		92%		65%	
Return for results (RR) overall	3,072	512	2,384	397	4,422	491
RR/TA	91%		69%		77%	'
RR/TP	78%		63%		51%	
Return for results: HIV-uninfected /TA			70%		82%	
Return for results: HIV-infected/TA			60%		62%	
Partners tested	22	4	41	7	70	8
Volunteers tested	10	2	34	6	36	4
HIV prevalence	13%		13%		14%	

It should be noted that there is a difference in ANC attendance between the projects, FSTI & Transition/Research and at the various sites. The lower numbers of ANC attendances and tests proposed is explained by:

- Short-cutting the testing facilities
- Language barrier
- Research did not include women < 18 years

A difference in test acceptability between the FSTI and the transition project is probably largely explained by group pre-testing in one site instead of individual counselling.

The change in the return rate between the various phases seems to be due to:

- Discontinuation of incentives, such as transport allowances and free medical care
- Fewer HIV-infected women returning
- Low numbers for partner testing

The results in FSTI according to the method of VCT are shown below:

VCT-method	Individu	ıal Pretest	Group Pretest		
	Total	Monthly	Total	Monthly	
ANC, new	6,049	712	2,028	369	
Tests proposed (TP)	3,857	454	2,028	369	
Tests accepted (TA)	2,584	304	376	68	
TA/TP	67%		19%		
Return for results (RR) overall	2,388	281	188	34	
RR/TA	92%		50%		
RR/TP	62%		9%		

The distribution of HIV prevalence by age during the transition project is shown in the next table:

Age group	HIV + / Pregnant Women Tested	Percentage
< 15 yrs	2/15	13 %
15 –19 yrs	65/903	7 %
20 –25 yrs	165/1149	14 %
25 –29 yrs	120/718	17 %
30- 35 yrs	65/398	16 %
35 - 39 yrs	22/187	12 %
> 39 yrs	8/66	12 %
Total	445/3436	13 %

The following table shows the proportion of HIV-infected women accepting AZT and BMS:

PMTCT indicator	Ditrame	Transition		FS	FSTI	
	Total	Total	monthly	Total	monthly	
No. of seropositive tests		445	74	814	136	
Return for results HIV-positive (RR+)		268	45	509	57	
AZT proposed		124	21	280	31	
AZT completed		100	17	150	17	
AZT proposed/RR+ve		46%		55%		
AZT completed/RR+ve		37%		29%		
BMS proposed	0	84	14	116	13	
BMS accepted		41	7	77	9	
BMS accepted/AZT completed	'	41%		51%		
Reduction of transmission	38%	?		2 + PCR		

The rate of return for AZT prophylaxis among HIV-infected women in both the transition and FSTI phases has been low. The reasons for this are not clear. There could well be a need for reinforcement of IEC messages.

There has also been a lower rate of AZT completed in both FSTI and the Transition projects. In FSTI, not all eligible women had received their AZT because they were less than 36 weeks gestational age.

Some women delivered before taking AZT.

There has been an increase in the practice of artificial feeding. This is probably due to:

- availability of BMS from the project;
- improved infant feeding counselling.

Feeding with a cup instead of a bottle is still not seen as an acceptable way of feeding an infant. There is need for proper follow-up of the artificially-fed children, to make sure that they are not suffering nutritionally.

Zimbabwe

Zimbabwe shared its experiences on VCT. Until about a year ago, no government centres offered VCT to the community outside of medical facilities. Only a few NGOs provided services in the field. Testing was offered at Blood Transfusion Centres for donors. Since about the beginning of 1999, several government and NGO facilities have started to offer VCT. These are mostly walk-in centres, which charge a minimum fee. The bulk of the clients are aged 20-34 years, with more males than females (ratio 1.6:1). Testing is performed using an ELISA test.

In Zimbabwe, almost 80% of pregnant mothers attend for at least one ANC visit. About 70% of deliveries take place in health institutions, either in primary health clinics or in hospitals.

The MTCT pilot project started around May 1999. So far, two maternity units in primary health care clinics have been included (one in Harare and one in a suburb of Harare, Chitungwiza). Three nurses per clinic have been trained in counselling.

In the two centres, group counselling on MTCT is given to all pregnant women in the form of health education during ANC visits. For women who volunteer for testing, individual pre-test counselling is given, which usually takes 15-60 minutes. On-going counselling is also offered. Nurses estimate that about 50% of their working time is spent on counselling. Because nurses have other duties, they are not always available for individual counselling.

AZT has been accepted and used by over 90% of HIV-infected women in the pilot project who are post-test counselled. So far, the majority have taken at least two weeks of AZT prior to delivery. Only one patient did not commence the drug until labour.

The reasons for the low uptake of counselling include:

- heavy workload of nurses
- lack of privacy during counselling
- stigma associated with approaching the MTCT counsellors
- social stigma outside the clinic
- lack of access to low-cost infant formula

The project has nevertheless attained various achievements, and is planning ways to improve uptake:

- > awareness has been raised, but more efforts are needed
- > 50 nurses have been trained in VCT/MTCT, not only in the pilot sites, but also in referral hospitals and other clinics. More training is required.
- > a support group for HIV-infected mothers has been formed at one site
- > income-generating activities are planned
- > closer attention to referral for psychosocial support is foreseen
- > a follow-up clinic for babies will be put in place

Rwanda

Rwanda discussed its experience of infant feeding counselling within the context of the pilot project at Kicukiro Health Centre. Counselling is given individually to HIV-infected women after they have received the results of their HIV test. This includes discussion of the advantages and disadvantages of breastfeeding vs. artificial feeding. The mother chooses the method of infant feeding.

So far, the majority of women (80%) have opted for artificial feeding. There is a local belief that breast milk is poison. Women who choose to breastfeed usually do so out of fear of stigmatisation.

All babies in the pilot project are followed-up as regards nutritional status. This takes place during visits for immunizations. A weekly visit is made during the first six months to infants of HIV-infected mothers who are artificially fed. Infant formula is given free.

The main lesson learned so far, is that artificial feeding does not seem to be a major problem in this population. The babies are growing well, and there have been no cases of severe diarrhoea or deaths.

Kenya

Kenya also shared its experience of infant feeding. The National AIDS and STD Control Programme estimates the HIV seroprevalence in the adult population in Kenya to be 13.9%; however, there are regions in the country with a prevalence of 20-30%. The current population of Kenya is 29 million people with about 50% aged less than 15 years. The seroprevalence among antenatal mothers varies from 3% in low prevalence areas to 35% in high prevalence areas.

The sites chosen for the Kenya PMTCT project are Homa Bay in Nyanza province, Karatina Hospital in Central Province and Kenyatta National Hospital in Nairobi Province. The percentages of pregnant women testing positive at the sentinel sites in these regions are 29%, 17% and 16% respectively.

At each of the sites breastfeeding is universally practiced and other feeds are introduced early to the majority of infants

To support PMTCT project implementation, a baseline knowledge, attitudes and practices survey was conducted in November 1998 with the following major findings:

- stigmatisation of HIV-infected persons by health workers and communities was common at all sites
- alternatives to breast milk are used when a mother dies (cows', goats' and camels' milk and soya products);
 formula milk, however, was not given as one of the choices.
- accurate knowledge on infant feeding was low among both communities and health workers (exclusive breastfeeding and complementary feeding)
- health workers expressed a need for training in infant feeding
- misconceptions are common regarding HIV transmission
- the socioeconomic status of the rural communities was low, with poor sanitation and hygiene
- there was a lack of both knowledge about and access to VCT services
- women are not empowered to make decisions

The presenter explained where the project is now:

- An integrated training package has been developed and used to train 30 trainers of trainers who, in turn, have trained 180 health workers at two sites
- Supplies have been received and delivered to most of the sites
- Health facilities are being improved to meet the needs for confidential counselling
- All data collection tools have been developed, including modification of the ANC card
- IEC materials development has followed the process of formative research, analysis, design of materials and
 production of drafts, which have been pre-tested in all three sites. Materials cover the themes of introducing
 PMTCT, VCT, stigma reduction, marketing of health facilities, support groups, individual counselling and
 awareness creation on primary prevention of HIV transmission.
- Kenya is ready to recruit the first client on the first of June 2000

Lessons learnt to date include:

- > Slow implementation reduces the high motivation of the health workers and communities
- ➤ The implementation of the pilot project is likely to increase general awareness of the options available to mothers and will lead to an increase in client load. This is important given that the sites experience staff shortages.
- There is a need to study and develop interventions to meet the psychosocial care and stimulation of the baby who will not be breastfed

The way forward:

- > The pilot project is taking advantage of the newly constituted National AIDS Control Council to advocate for increased resource allocation and for government to take a more active role in project implementation and monitoring.
- > The project will undertake a cost analysis study that will inform on the various costs to the implementers as well as to the mother and to the community. This will provide important information for scaling up.
- A study on alternatives to breast milk at community level is planned.

South Africa

South Africa gave an overview of the care and support within the Perinatal HIV Unit at Baragwanath Hospital in Soweto. The Perinatal HIV Unit provides counselling 24 hours a day by training every health worker in the unit for back-up. It has made it a point to employ male counsellors for male-to-male counselling. This has encouraged most women to disclose their status to their partners. The unit is starting to see more men attending the clinic. Behaviour change and disclosure are still challenges in counselling.

Support groups are run every Wednesday in the unit, in collaboration with NGOs. A group of PLWHAs, called ACCT (which used to be called Wolanani) are involved in care and support. Some of the women in this NGO have been involved in the unit's MTCT trials.

All pregnant women who receive antenatal care at Baragwanath Hospital are offered routine HIV testing. Uptake of the test is over 90%, and HIV seroprevalence in mid-1998 was over 20%. After the trial some women are put on anti-bacterial prophylaxis.

The unit has started a community group, sponsored by HIVNET, to prepare the community for a vaccine trial. This group will work to educate the community about research in general, and what research is ongoing and what is planned. This interaction has taught the unit that it is essential to work with the community before starting any research

The unit provides antenatal and postnatal care for women, follow-up for gynaecological problems, family planning advice and provision, peer group counselling and access to community organisations and support groups. Counselling and testing is provided for male partners of HIV-infected women, and women are encouraged to bring partners for couple-counselling. Children born to infected mothers are followed until 18 months, and have repeat tests during this period to determine their HIV status.

Offering care and support has been the best way to help those who are HIV-infected, and others who are affected by the illness, to improve the quality of their lives, to disclose their status, and most of all start feeling that life is still worth living. The unit must ensure that it plans, budgets and provides infrastructure for those who need it most, and thereby make a difference. It is best if PLWAs should be involved when proposals are being written. The unit will soon be starting a pilot project called DART in partnership with the South African government, and will be funded by FSTI (French Government).

Uganda

Uganda spoke of its experience with care and support. The country has selected seven sites for pilot project implementation, three within the capital city (Kampala), and four distributed up-country. Preparatory work has been done at all sites. Two are operational, and training at the third site has begun.

It is the government's policy on care and support for PLWHAs to promote a continuum of comprehensive care. VCT has been offered mainly by NGOs, although the government has a programme for country-wide expansion. NGOs, community-based organisations (CBOs) and the government carry out clinical management, nursing care and counselling. Social support is chiefly provided by NGOs and CBOs.

It is foreseen that mothers in the pilot projects should ideally receive the following care: comprehensive antenatal care (screening for anaemia and sexually transmitted infections [STI], infant feeding counselling); labour and delivery care (modified obstetric practices,); post partum care (family planning and prevention of HIV, breastfeeding counselling); and social support through referral to NGO/CBO support groups.

Care of children will include monitoring of growth and development; counselling on breastfeeding (including the risk of prolonged breastfeeding by HIV-infected mothers); social support at community level; access to social services, including health care; and addressing issues such as protection and inheritance.

1,111 women have so far been counselled at the two pilot sites which are operational. 668 have been tested for HIV (106 refusals) and of these 106 women were HIV-infected. The overall seroprevalence rate is 14%. Of 46 women scheduled for enrolment in the project, 28 have actually started and 15 have delivered. As regards feeding options 38% of HIV-infected women have chosen exclusive breastfeeding, 47% formula and 15% were undecided. None said they would mix feed.

General challenges in implementation include:

- > training staff in MTCT while continuing to provide services;
- > integration of services into ANC i.e. understaffing, increased workload and a need for extra space;
- > coordination of activities within and across sites;
- > slow procurement of equipment and supplies; and
- > promoting male involvement.

Challenges related to care and support include:

- identification of mothers without creating stigma;
- issues of confidentiality, with regard to the individual in relation to the institution;
- > stigma from health workers, and for mothers who decided not to breastfeed;
- ➤ how to motivate health workers without paying special allowances;
- > establishing a continuum of care for mothers.

Tanzania

Tanzania presented how guidelines on MTCT have been developed. The scale of the problem in the country is set to have a dramatic and deleterious impact on child survival. Using an HIV prevalence rate of 12% for antenatal women and a total vertical transmission rate of 40%, it is estimated that 72,000 babies will be infected with HIV each year (approximately 25,200 through breastfeeding). Ten per cent of these babies would have died anyway in the absence of HIV in their first year of life from childhood infections. MTCT, therefore, accounts for an additional 64,800 child deaths. This represents a 43% increase in infant mortality in addition to the current 150.000 child deaths from common childhood infections.

The first consultation on MTCT in the country took place in April 1998. This UNICEF-supported consultation, held at the Reproductive and Child Health Unit of the Ministry of Health (MOH), reviewed the implications of MTCT on programming for child health in Tanzania. The consultation concluded that an assessment of opportunities for activities should be undertaken in the likely sites. A thorough situational analysis of four hospitals (Muhimbili Medical Centre, Kilimanjaro Christian Medical Centre, Bugando Medical Centre, Mbeya Referral Hospital) was started in July 1998.

Through a series of reviews and consultations involving the expertise of a wide range of individuals, five sets of guidelines were produced by mid-July 1999. These guidelines include:

- Guidelines on infant feeding that took into account the specific circumstances of HIV-infected women. These guidelines have been widely circulated and acknowledged as helpful. Content includes:
 - > explaining the situation to the client
 - > discussing the mother's particular situation
 - > explaining the options for infant feeding
 - > making the decision
 - helping the women to identify potential support and opposition
 - protection from re-infection
 - > plan for future appointments
 - issues for discussion in subsequent counselling sessions:
 - non-use of contraceptive barrier methods
 - breast milk substitutes
- Obstetric care guidelines, which aim to promote care of women during the antenatal period and labour and minimise MTCT. The use of these materials will go beyond the five pilot sites. Content includes:
 - introduction
 - ➤ HIV infection in pregnancy
 - > factors influencing mother-to-child transmission of HIV
 - modified obstetric care for HIV-infected women
 - post abortion care
 - ➤ HIV-negative women
 - universal precautions
 - promoting, protecting and supporting breastfeeding among HIV-uninfected mothers
- Counselling guidelines that took into account the increased workload (requiring increased deployment of
 counsellors, among other things) resulting from the installation of MTCT interventions at the health facilities
 as well as the quality of interpersonal communication between health workers and their clients. Content
 includes:
 - introduction
 - objectives
 - basic facts about HIV/AIDS
 - basic concepts of counselling
 - counselling with emphasis on HIV/AIDS
 - support for the counsellor
 - supervision
 - professional ethics
 - prevention of HIV
 - networking
 - nutrition /dietary counselling
- User-friendly laboratory algorithms for HIV testing, recognising especially that confidentiality, speed and quality need to be maintained and assured.
 - introduction
 - > sample collection
 - > testing algorithm for pregnant women
 - > choice of simple/rapid assays suitable for Tanzania
 - > testing procedure
 - early diagnosis of HIV infection in children

- > quality control
- > other laboratory tests
- procurement and storage of test kits and reagents
- An effective monitoring and evaluation framework capable of tracking the process and impact of the interventions as well as the rational use of ARV drugs.
 - introduction
 - objectives
 - monitoring
 - data collection, entry and analysis
 - description of registers/record forms
- Tracking the rational use of ARV drugs.
 - introduction
 - objectives
 - common security breaches at hospital level
 - > systematic search for security breaches
 - documenting the use of ARV drugs
 - collection of ARVs from the pharmacy

The teams that formulated the different guidelines presented their proposals to a workshop of participants from the five sites, the MOH, UNICEF, UNAIDS, SAREC, Medecins du Monde and others. Representation from the pilot sites was broad, generally carrying the following profile of participants: the hospital directors, the nursing officers in-charge, paediatricians, obstetricians, pharmacists, microbiologists, counsellors, and midwives in antenatal, maternity and paediatric wards.

The lessons learned through this process include:

- Ministry of Health commitment and participation has been evident
- Sites' participation and ownership has also been achieved
- Shared experience from PETRA (Perinatal transmission study) has been valuable
- UNICEF commitment was supportive
- Family planning advice and provision is essential

Honduras

Honduras shared its general experience in getting started. Between 1985 and October 1999, a total of 14,230 HIV-infected persons and 11,021 AIDS cases have been reported. In 1997, 0.7% of pregnant women in Tegucigalpa were HIV-infected. In 1998, the seroprevalence in prenatal care clinics in San Pedro Sula was 3.6%. From 1987-1992, 105 children with perinatal-acquired HIV/AIDS cases were seen. Between 1993-1998, 514 children were diagnosed with HIV infection.

The main objectives with regard to MTCT include:

- to implement a pilot programme in Tegucigalpa and San Pedro Sula for two years that will reduce MTCT by 50% in non-breastfeeding women and by 35% in breastfeeding women, without increasing infant morbidity and mortality, nor impairing infant growth;
- to develop institutional capacity to combat MTCT.

The target population in the two cities is 56,355 pregnant women, of whom 80% attend prenatal care. It is hoped to reach half of these women in the first year. The pilot will include twelve health centres and two hospitals in the capital city, Tegucigalpa, and four health centres and three hospitals in San Pedro Sula.

The basic intervention package will include:

- IEC activities
- VCT
- short-course AZT
- provision of prenatal multivitamins
- obstetric measures
- counselling on infant feeding
- provision of breast-milk substitutes for women who decide to use it
- growth and development monitoring of the child (monthly)
- testing of infants
- family planning services
- psychosocial support

Four main areas of weakness and/or where major implementation questions have arisen:

- IEC:
 - > for health workers (counsellors, doctors): information workshops, training, distribution of information, in a continuous process, on the theme of MTCT and the pilot programme;
 - > for pregnant women: information in health centres, posters, on the themes of HIV transmission and prevention, HIV tests;
 - > for HIV-infected pregnant women: counselling, leaflets, on the themes of prevention of transmission and the pilot programme.
- Delivery Care:
 - > confidentiality vs. identification of HIV-infected women in hospitals;
 - deliveries in septic (semi-isolation) ward for asymptomatic HIV-infected women;
 - rooming-in and infant feeding in the case of Caesarian-section;
 - AZT treatment during delivery.
- Tests for HIV status:
 - rapid tests: these are very expensive when bought locally, and there is no experience in their use in the public sector and especially in health centres;
 - polymerase chain reaction (PCR) testing: it would be desirable to have early diagnosis in newborns, but PCR testing is very expensive.
- Psychosocial support:
 - > counsellors exist in the health centres:
 - > self-help groups needed, and first contacts have been established.

Botswana

Dr. Loeto Mazhani spoke about the MTCT programme in Botswana in light of the recent review and plans for scaling up. He first of all described the magnitude of the problem in the country, with:

- high HIV infection rates: 19% in the general population, 29% in adults 15-49 years, and 36% prevalence in women attending ANC clinics;
- 34% of paediatric admissions in referral/urban hospitals and 70% of paediatric hospital deaths are HIV-related:
- 48-65,000 births annually in Botswana assuming 40% transmission rate, then approximately 7-9,000 children are infected yearly.

The national response has included:

- > carrying out of a situation analysis
- > establishing the PMTCT programme in 1998 with an annual budget of US\$3.5 million
- > piloting in Francistown and Gaborone started in April 1999
- > scaling up nationally planned for 2000

The PMTCT programme incorporates:

- > IEC, as a prerequisite for informed decision-making, and as both a preventive and interventional strategy;
- ➤ voluntary counselling and testing (VCT), as the cornerstone (but also limiting step) of the intervention. The goal is to offer VCT routinely and in an integrated manner to all ANC clients;
- ➤ HIV testing, on a voluntary basis after counselling, using ELISA as the routine method of testing, but with rapid tests in emergency situations, that is, where a woman is first tested after 32 weeks gestational age;
- > drug protocol for HIV-infected women: oral AZT (300 mg) twice daily starting at 34 weeks of pregnancy and every three hours during labour; intravenous AZT during labour for those unable to tolerate oral AZT; AZT syrup (4mg/kg) twice daily to infants from birth to one month of age;
- > obstetric interventions, including modified obstetric practices that minimize the risk of transmission of HIV during delivery. Routine caesarian section is not part of these practices;
- infant feeding, including recommending infant formula instead of breastfeeding for HIV-infected mothers. Formula is offered from MCH units for the first six months, with provision beyond this time possible depending on the socioeconomic circumstances of the mother.

The uptake of the programme from April 1999-February 2000 is shown in the following table:

	Gaborone (%)	Francistown (%)	Total (%)
New ANC cases	4866	3915	8781
No. counselled	3267 (67)	1811 (46)	5078 (58)
No. agreed test	1231 (38)	1094 (60)	2325 (46)
No. with results available	1192	893	2085
No. HIV positive	434 (36)	395 (44)	829 (40)
No. children born to HIV-infected mother	185	301	486
No. HIV-infected women given AZT	109	178	287
No. children given AZT	178 (96)	269 (89)	447 (92)
No. children on infant formula	174 (95)	178 (59)	352 (72)

The mean age of mothers is 26 years (median 25 years). The mean and median gestational age at first visit was the same at 20 weeks.

There was no local baseline data on the rate of MTCT for Botswana, so the country assumed it would be 40%, based on studies from other countries. A sample of 400 children born to HIV-infected mothers participating in the programme is being followed to determine the transmission rate and outcome. In this cohort of children, PCR is being carried out at birth, two months and 6 months of age, with an ELISA test at 18 months. Preliminary transmission data for 111 babies at birth was 9.1%.

During the review after eight months of operations, the strengths of the programme were identified as:

- the programme is population-based (the first one in Africa)
- a high level of commitment from Government, with an annual budget of US\$3.5 million
- MTCT is being integrated into ANC services of a high standard (including syphilis screening and treatment, and routine haemoglobin determination) in a strong health care system
- good obstetric and gynaecological practices (episiotomies and artificial rupture of membranes are not practiced routinely)
- good laboratory services for HIV testing
- some IEC activities are being carried out, albeit they are inadequate
- community mobilisation has begun

However, several constraints were also identified:

- uptake of the programme is low
- fear of HIV test results inhibits promotion and acceptance of the programme
- IEC strategy for both the public and health workers is not sufficiently developed
- IEC messages have been unclear and inadequate
- community support for the programme and for HIV-infected women has not been sufficiently generated
- counselling is inadequate in terms of availability, content and quality
- only one-half of ANC clients have been counselled, only one-half have agreed to testing
- only one-third of the women who entered the programme so far, received an adequate dose of AZT
- health workers are not clear on the infant feeding message to be conveyed
- follow-up of clients is inadequate
- the monitoring system is complicated and perceived as cumbersome

Based on the review, the country has decided to:

- > re-programme and strengthen implementation strategies and activities
- > expand the programme to other districts starting in July 2000
- > strengthen networking and partnership with other interested parties
- > review the drug protocol and define the role of other interventions, such as NVP

Discussion and lessons learned

The main discussion points after all the country presentations related primarily to VCT and MCH included:

- Integration of PMTCT into MCH services still needs research, and this should be closely coordinated between donors and implementing countries.
- Men must be involved in VCT, and therefore IEC materials should be developed towards this goal. Men's
 involvement is likely to reduce stigma towards HIV-infected mothers.
- Zambia had developed IEC materials for men on PMTCT. Communities had suggested ways of reaching men,
 e.g. through church gatherings and couple counselling.

- The training programme for Zimbabwe requires expansion. The VCT training took three weeks. They have built on their existing HIV/AIDS counselling course. More health workers have been trained to handle the increasing workload due to counselling.
- Zimbabwe is currently using ELISA tests for HIV screening. It is not possible to urgently screen a woman in labour. They are currently evaluating rapid tests, and they will soon be available in the country.
- The Rwanda programme followed-up children weekly for the first six months.
- Lay counsellors have been utilised in HIV counselling in South Africa. PLWHAs are trained in counselling
 and provide the service with guidance from a psychologist. Younger men performed better in counselling than
 older men
- It is important that the same person who provides pre-test counselling provides post-test counselling as well.
- There was concern that most Mozambican women (60%) do not deliver in health units. They hope to reach them through targeting adolescents.
- Mozambique does not yet have the capacity to provide VCT for pregnant women. The available kits are not
 adequate for even half the pregnant women.
- Botswana is concerned about the low acceptance of testing despite the services being available. A survey is being done to determine the hindering factors.
- The drop-out observed in Botswana may not be significant, with the programme having been in place for only one year. With better IEC, the acceptance rate for testing should go up.
- It was the experience of Cote d'Ivoire's that one week's training for midwives was not sufficient. Two-weeks of counselling training with experienced counsellors provides the midwives with confidence to carry out the services.
- There was concern that the uptake of cup feeding in Côte d'Ivoire was low. Mothers gave infants water and breast milk, and exclusive breastfeeding was rare. The response was that exclusive breastfeeding must be encouraged. Cup feeding is widely practiced in many countries and is feasible.

The lessons learned from the countries about implementing PMTCT include:

- it is not necessary to wait for everything to be in place, but countries should build on what is already on the ground
- community consultation and participation is important
- it is important to involve PLWHAs
- VCT is the cornerstone of MTCT
- counsellors should be well-trained, supervised and supported
- health workers need training on infant feeding
- mothers need support and follow-up, especially with respect to infant feeding
- studies and interventions are needed on the psychosocial care of people with HIV and their families
- MTCT should be integrated into routine health care services

Main opportunities were identified:

- Financial commitment from governments and cooperating partners
- > NGOs and CBOs already present in communities to help with VCT and social support
- lesson from all the pilot countries

Some of the challenges include:

- > fear of HIV results impairs the promotion and acceptance of the programmes and leads to low uptake
- > stigma
- how to involve males
- > motivation of health workers in light of increased workload
- > establishment of a continuum of care for mothers
- > need to develop integrated guidelines and training manuals with country adaptations

SESSION 4: PROGRAMME AND TECHNICAL RESOURCES

Strategic Framework for Pilot Projects on PMTCT

Elizabeth Hoff of WHO presented the document which has been developed by the Inter-Agency Task Team on PMTCT and provides the framework within which the current pilot projects are supported. It is a synthesis of the technical and managerial considerations that are required for initiating a model project on PMTCT of HIV. These considerations can serve as a checklist for countries that are planning to initiate or expand projects. The document is intended for programme managers, supporting agencies, funding agencies and other partners and stakeholders in PMTCT. As experience is gained from the pilot projects, the document will be regularly updated.

Clinical Guidelines

Ms. Hoff also presented four (draft) documents that are intended to assist health workers who are responsible for caring for women antenatally, during delivery and postnatally. They cover the following areas:

- ♦ Antenatal care for HIV-infected women
- Voluntary counselling and testing for HIV in the maternity setting
- ♦ Labour and delivery care
- Post pregnancy care of the HIV-infected mother and her infant

The guidelines highlight the opportunities during antenatal, delivery and postnatal care to reinforce primary prevention of HIV, to detect and treat STIs and stress the benefits for pregnant women and their partners of knowing their HIV status. They also cover the specific care requirements of HIV-infected women, including prevention and treatment of HIV- related infections during and after pregnancy; specific measures during delivery including the use of ARVs to reduce the chance of transmission; counselling for future reproductive choices; and ongoing care and support for the mother and baby after delivery.

Tools for evaluating HIV voluntary counselling and testing

Rachel Baggaley of WHO presented a document which provides guidance on monitoring and evaluation of various aspects of planning and implementation of VCT. It provides tools for the evaluation of VCT as part of a national programme, as well as VCT services at specific institutions, independent sites and services for special groups, including community-based NGOs. It includes monitoring and evaluation of VCT services associated with PMTCT and tuberculosis preventive therapy. The document revises and adapts previous draft guidelines and incorporates relevant operational research findings.

HIV Testing

Jean Michel Gershy-Damet of AFRO discussed the issues that must be considered when choosing diagnostic HIV tests in the context of VCT for pregnant women:

- operational factors such as: available laboratory infrastructure, available equipment to perform tests; technical skills of staff; number of tests to be performed; and cost.
- sensitivity and specificity of tests
- ♦ prevalence of HIV infection in the population: WHO advises to use strategy II (see below) for diagnosis of HIV in asymptomatic clients in populations with a prevalence of 10% or more, and strategy III if the prevalence is below 10%. In strategy II, all serum is first tested with one ELISA or simple/rapid assay, and any reactive samples are retested using a different assay. Serum that is not reactive in the first test is considered HIV antibody negative. Serum that is reactive in the first but not in the second assay should be tested again with both tests. In strategy III, a third test is required if serum is reactive on the second assay or on the repeated first assay. The tests used in strategy II or III should be based on different antigen preparations and/or different test principles.

The following table compares logistical considerations of ELISA and rapid/simple tests:

	ELISA	Simple/ Rapid tests
Availability of results	Usually after 1-2 days or more	Lateral flow tests: <15 minutes
		Other simple/rapid tests: 30 min to 3 hours
Number of samples	> 40 daily (1/2 ELISA plate)	< 40 daily
		(not more than 90 tests/day)
Facilities	Equipment, electricity, water	Limited facilities
Technical skill of staff	Skilled laboratory staff	Can be performed by non-laboratory staff
Storage conditions	2-8 C	Some S/R tests can be stored at 25-30 C
Kit size	96, 192, 450, 576 tests	20, 30, 50, 100

Quality assurance should include monitoring the performance of the test as well as the performance of the operator who carries out the test. Internal quality controls need to be included daily or with each run of the test. Results of a proportion of specimens should be checked in another laboratory. However, many problems are not due to the manufacturer: staff must follow standard operating procedures; equipment has to be maintained and calibrated; and supplies and equipment must be correctly stored. Measures are needed to avoid clerical or transcription errors.

Counselling Course on HIV and Infant Feeding

Dr. Savage announced that the UNICEF/WHO "Counselling Course on HIV and Infant Feeding" will be launched in Harare on 3-7 April 2000. The course is based on the WHO/UNAIDS/UNICEF guidelines on 'HIV and infant feeding' published in 1998. The training is for counsellors, mainly health workers, who counsel HIV-infected mothers on the risks of different feeding options, including breastfeeding, modified animal milk and commercial formula. The participants should already have adequate knowledge on breastfeeding counselling, since not all aspects of breastfeeding counselling are dealt with on this course.

During the first three days of the course, participants from eight countries in the region will be trained on HIV and infant feeding counselling, and it is expected that they will be involved in their own countries as trainers of counsellors. The last two days of the course will focus on organising the HIV and infant feeding counselling course at country level and on planning other aspects of HIV and infant feeding, including policy development. The country teams are expected to develop detailed action plans on HIV and infant feeding for their countries.

Communication Strategy

Sylvia Luciani from UNICEF New York presented on different aspects of communication. She described the role of communications in PMTCT as: creating awareness; increasing knowledge; influencing attitudes, norms, values and behaviour change; and creating a supportive environment. Potential partners in communications include governments, UNICEF, WHO, UNAIDS, UNFPA, NGOs/CBOs and other resources.

The Communications for Development Model includes:

- ♦ Advocacy: to ensure political and social support
- Social mobilisation: to forge alliances and partnerships
- Programme communication: targeted communication for behaviour development

More specifically, the ACADA communication planning process includes:

- Assessment: produce a situation report
- Communication analysis: define communication objectives and M&E indicators
 - problem analysis/statement
 - behaviour analysis
 - > participant analysis
 - channel analysis
- Design: develop a strategic plan for advocacy, social mobilisation and programme communication
 - > select partners, channels, approaches, activities
 - develop messages and materials
 - develop dissemination and training plan
 - develop monitoring and evaluation plan
 - develop plan of action
- ◆ Action: implement the plan
- Evaluation

Areas of special focus include:

- Importance of the assessment phase
- Analysis of all programme participants' attitudes and behaviour is fundamental
- Use of participatory and qualitative research methodologies
- At pilot phase, focus on targeted approach to avoid creating demand on a national scale
- Importance of inter-personal communication
- Communication objectives to be measurable and entail knowledge, attitude and practices change among participants
- Focus on creating a supportive environment
 - > work with families (sexual partner/husband, mother/mother-in-law, sister, aunt, grandmother)
 - work with CBOs, religious groups, local leaders
 - > actively involve the community and persons affected by HIV/AIDS in communication planning and implementation
- Identify and integrate communication specialists within country PMTCT teams
- ♦ Special attention to adolescent girls

Communications support in various areas will be needed:

- ♦ Technical communication experts
- Analysis of existing communication strategies and their implementation
- Review of tools, other resources
- Workshop on communication to share experiences and fine-tune strategies
- ♦ PMTCT communications e-network
- Global prototypes of advocacy materials

Discussion

There was concern that VCT evaluation tools focused more on knowledge than on counselling skills. In previous studies gaps were identified on the knowledge of the counsellors and the need to balance the two.

A question was raised on how feasible it is to collect the VCT data suggested in the evaluation forms? It was explained that most information is not meant to be obtained routinely from every counselling session. The information could be useful for training and random samples can be used.

The need to integrate counselling services on breastfeeding, HIV, etc., was expressed.

SESSION 5: LESSONS LEARNED AND EMERGING ISSUES

The purpose of session 5 was to give countries an opportunity to discuss in detail some of the areas that needed extra focus or which seem to be problematic. Six topic areas were identified from the presentations and discussion of the first day. These were: (1) communication, (2) VCT, (3) infant feeding, (4) care and support, (5) ARV drugs and

(6) HIV tests.

Two facilitators were assigned to each group. Topics 1, 2 and 3 were discussed in the morning session and topics 4, 5 and 6 in the afternoon.

The main issues suggested for group discussion were:

- What are the different models/standards which countries have adopted/plan to adopt?
- How and why do these differ from international recommendations?
- What are the constraints encountered so far?
- What are the positive experiences so far?
- Are there special implications for staffing?
- Are there special implications for budgets?
- What is being done about quality control?
- What can be recommended to other countries?

The feedback of the groups has been combined with the feedback from session 7.

SESSION 6: FIELD VISITS

For the field visits, participants split up into 6 groups, each going to a different public health facility in Gaborone. Individuals in each group were asked to pay particular attention to one of the topic areas, and try to gain information on what was actually happening in that area.

SESSION 7: ISSUES REVISITED

The three groups (Communication, VCT and Infant Feeding) of the morning session of day 2 reconvened and observations from the field visits were introduced into the discussion. Comparisons were made between what is happening in Botswana and in other countries, and some conclusions and recommendations were formulated.

Communication

The group identified the following key issues related to communication for PMTCT:

1. COMMUNICATION STRATEGY

Countries are at different stages of development and implementation of communication strategies for MTCT. The range is wide: from absence of a strategy, to ad hoc interventions, to more systematic planning approaches, such as the ones being developed/implemented in Zambia, Botswana, Kenya, and Zimbabwe. Development of measurable communication objectives is extremely limited, which represents a constraint to future evaluation of the impact of communication strategies. Communities and PLWHAs are not systematically involved in communication planning, development and implementation.

2. GETTING COMMUNITIES ON BOARD AS PARTNERS

There is a variety of interesting experiences in reaching women, their sexual partners, families and communities – these need to be captured and shared. There seem to be only vague ideas about their effectiveness in producing behavioural change and in mobilising communities. Efforts should be made to actively involve PLWHAs and men.

3. COORDINATION AMONG PARTNERS IN PMTCT

Communication specialists or focal points should be included in the country PMTCT teams and communication should be an integral part of PMTCT interventions. Communication for PMTCT should be integrated within the overall HIV/AIDS communication strategy.

4. QUALITY CONTROL AND M&E

Communication interventions should be systematic, strategic, research-based and should have measurable objectives. Tools and indicators need to be developed, including the involvement of men. Messages should be consistent between related programmes (Safe Motherhood Initiative, Baby Friendly Hospital Initiative, Integrated Management of Childhood Illness).

TRAINING

PMTCT country teams have to be trained in communication planning. At implementation level, the service providers need training in inter-personal communication and counselling skills.

6. COMMUNICATION EQUIPMENT

Use of innovative channels of communication should be encouraged (phone info-lines, radio call-in programmes, e-mail, internet, video). Equipment can be shared with other communication interventions.

The role of communication in PMTCT was discussed extensively. It was agreed that communication should:

- reinforce primary prevention
- support advocacy at various levels, presenting PMTCT as a human rights issue and influencing policy makers
- > support resource mobilisation
- > prepare communities to accept PMTCT interventions and to become involved
- > empower potential clients to request PMTCT and make informed and responsible decisions
- > promote male participation in VCT and decision making
- > mobilise service providers to lead by example
- reinforce adherence and client compliance to chosen options to reduce MTCT
- > reduce stigma and fear

The following activities related to communications were suggested for implementation at country level:

- > make an inventory of available resources, both human and financial
- document and share experiences and lessons learnt
- > develop guidelines and tools for communication
- > seek technical and financial support for communication research
- > train country PMTCT teams in communication strategy
- intensify advocacy with national governments and partners at the highest level for support

VCT

Five pilot countries have started VCT services and were able to share their experiences. The following issues were highlighted:

1. MODELS

Different models of VCT are being used successfully in the various pilot settings. All have advantages and constraints. Uptake rates of counselling and acceptance of testing vary between sites. As these factors are important determinants in the success of the MTCT projects, it is important to identify reasons for these differences and develop services accordingly to make VCT-MTCT interventions more acceptable to women in very high prevalence countries. It is also useful to analyse the significance of both operational factors and community and health care worker attitudes. It was noted that most pilot projects are currently in urban areas, and there is very little experience from rural areas where issues of health worker-client confidentiality may pose different challenges in small, closely-knit communities.

2. DISCLOSURE

Sites reported varying rates of disclosure of HIV test results to male partners/fathers. It was acknowledged that disclosure to sexual partner/s was helpful in discussion of issues around MTCT and for making safer sex and future reproductive choices. However, many women felt unable to involve their partners, because they feared abandonment or abuse. The counsellor, therefore, should always support a woman's decision about disclosure. Although there were reports from Cote d'Ivoire of marital break up following disclosure , other sites reported that, despite fears about the possible negative consequences of testing, very few had actually been experienced. It will be important to carefully monitor the positive and negative events following VCT and not to merely rely on anecdotal accounts.

3. TRAINING

Most programmes consisted of an initial 1-2 weeks of residential training. This was often reported to be too theoretical with inadequate emphasis on skills training which resulted in some counsellors lacking confidence when they returned to their clinics. Some sites employed a senior counsellor to provide support to newly-trained staff during their first weeks of counselling. Regular support, feedback and supervision sessions were considered essential if counsellors were to provide services of high quality. Sharing of curricula was also proposed, so that countries could benefit from each other's experiences and ideas.

4. WORKLOAD FOR COUNSELLORS

Counselling has added an additional task to health care staff working in antenatal clinics. Several solutions have been proposed:

- Broader recruitment of counsellors to include PLWHAs, lay and volunteer counsellors. Lay counsellors have been used in some settings, and in many countries peer support groups have provided ongoing emotional support for people following VCT. It is important, however, if lay counsellors are used that they receive adequate training, support and supervision to ensure that they provide high quality counselling and do not become stressed by their work or suffer burnout. Peer counsellors, especially those with HIV, may be vulnerable to burnout if they do not receive adequate support.
- More appropriate training in basic counselling skills. Although MTCT counsellors had received training, it was often described as being too theoretical. Counsellors lacked basic skills to deal with common situations in post-test counselling (for example, skills for managing difficulties following breaking bad news, disclosure issues, sero-discordant couples, and HIV prevention counselling). Furthermore, many MTCT counsellors were themselves unsure about the benefits of VCT for MTCT interventions and were thus sometimes projecting contradictory messages to women attending ANC. If their skills were more appropriate and focused, MTCT counsellors would feel more confident about providing VCT, counselling sessions would be of higher quality, and uptake may consequently be higher.
- Better professional support for counsellors' roles. Many MTCT counsellors feel unsupported and unappreciated in their counselling roles. The importance of making their roles understood and valued by other health staff was emphasized.
- Supportive supervision to maintain high quality counselling. Supervision and monitoring of counselling sessions was agreed to be important in order to maintain quality of sessions. UNAIDS tools for evaluation are available to assist in periodic review of counselling services.
- Community referral networks for ongoing counselling and psychosocial support of those adjusting to HIV. It was acknowledged that MCH services are often inappropriate places for ongoing counselling and emotional support for women and their families following VCT. It is therefore important to form strong links with community organisations, support groups and NGOs where relevant support can be provided.
- Shorter pre-test counselling/no pre-test counselling. Sometimes women who are well informed about the benefits of VCT and have discussed the issues with their families may not wish pre-test counselling. Where appropriate and when information from other sources is adequate, short pre-test counselling or consent may be adequate for some women. This may become a more usual

model when communities are well informed and have participated in the development of the MTCT VCT programme, or as the programmes become better established and participating women have friends and relatives who have been through the PMTCT intervention already.

5. INVOLVEMENT OF MEN

MTCT interventions have necessarily focused on women. For the full benefits of VCT and MTCT to be realised, involvement of husbands/partners/families must encouraged from the beginning. There is, as yet, very little experience of partner involvement and very few men are currently taking part in VCT or decision-making around MTCT interventions. In places where VCT is available though not associated with ANC services, it is suggested that much greater cross referral be made so that couples can test outside the ANC clinic, either prior to conception or during the antenatal period. Where the ANC services are the only VCT sites available, a much greater effort must be made to reach men, as little thought has been given so far to this important challenge.

6. SUPPORT AND ADEQUATE COUNSELLING FOR WOMEN WHO TEST NEGATIVE

Because the main aim of VCT associated with the MTCT interventions is to identify seropositive women in order to offer interventions, the importance of providing adequate counselling and ongoing support for women who test seronegative is often overlooked. It is important that women who test negative are counselled about HIV prevention and the benefits of discussing HIV testing with their partner. Serodiscordancy has been reported in up to 25% of couples, leaving many women vulnerable to future infection

INFANT FEEDING

1. TECHNICAL ASPECTS OF INFANT FEEDING

Scientific knowledge on the adequacy of the several feeding options is still incomplete; these uncertainties hamper clear counselling of HIV-infected mothers by health workers. There is a tendency in the MTCT health facilities to restrict the feeding options to either formula feeding or breastfeeding. In some facilities, in particular those where formula is available, there is a tendency for health workers to promote the use of formula as the only good infant feeding option.

Not much attention is given to the importance of exclusive breastfeeding or exclusive alternative feeding. In many cases counselling does not support mothers who decide to breastfeed by giving them technical support to carry it out optimally. Consequently, mixed feeding often takes place, which may increase the risk of MTCT as well as diarrhoea and other infections.

2. LOCAL FEASIBILITY RESEARCH

Little is known about which feeding options are feasible and under what circumstances, because the target group of the counselling has not (usually) been involved in the development of infant feeding policy and guidelines.

INTEGRATION OF FEEDING OPTIONS INTO BROADER BREASTFEEDING PERSPECTIVE

Breastfeeding promotion including advocacy and implementation of the BFHI and International Code of marketing of breast milk substitutes has weakened during the last few years as a consequence of the increasing attention to MTCT of HIV through breastfeeding. Confusion exists among the public in general, and in particular mothers of infants and health workers, due to perceived conflicting messages on infant feeding including breastfeeding.

4. INTRODUCE AND STRENGTHEN INTEGRATED INFANT FEEDING TRAINING FOR ALL HEALTH WORKERS

It is not enough merely to provide information on infant feeding options to HIV-infected mothers and to leave them to make a decision. They often request advice from the health worker on what option they should choose. Health workers who are required to counsel mothers on infant feeding often have very limited training on either breastfeeding or other options, and are not able to help the mother make a balanced decision.

5. SUPPORT PARTICIPATION OF COMMUNITIES IN DECISIONS ABOUT INFANT FEEDING

In order to provide solutions to some of the problems identified, the working group concluded the following:

National programmes with the support of WHO/UNICEF/UNAIDS/UNFPA and in collaboration with other partners should ensure that:

- 1. Training on infant feeding is strengthened and accelerated for all health workers who care for mothers and babies, including PMTCT counsellors. The training should include breastfeeding counselling, complementary feeding, infant feeding in MTCT, and replacement feeding options. Breastfeeding specialists need to be more actively involved in training for infant feeding counselling as part of PMTCT.
- 2. Studies on the feasibility of the several feeding options for infants (up to 12 months old) in the local situation are conducted. These studies should include assessment of decisions made and feeding options chosen by HIV-infected mothers counselled on infant feeding during the last year. The community and PLWHAs should be included in the development of infant feeding policies and guidelines.
- 3. Counselling on infant feeding and PMTCT is designed to enable the mother, in consultation with the health worker, to decide on what infant feeding option is most feasible for her and best for her infant. To facilitate this, an infant feeding options checklist will be developed. The aim of the counselling is more than just providing information and expecting the mother to make a choice without assistance to assess the appropriateness of the alternatives.
- 4. Aspects of infant feeding covered in PMTCT /IMCI /BFHI /SMI are integrated at organizational level and the content of each is revised to ensure that all initiatives disseminate consistent messages and strengthen each other.

TESTING

The following were identified as critical issues regarding HIV testing in PMTCT

- 1. rapid tests should be encouraged
- 2. clarification on the use of PCR in the diagnosis of HIV infection in infants and young children
- 3. guidance on who can perform the rapid tests (laboratory staff, health workers, lay counsellors)
- 4. quality assurance needs to be strengthened
- 5. how reagents should be procured

CARE AND SUPPORT

- 1. Important aspects of care and support that an HIV-infected woman might require include:
 - preventive therapy for bacterial infections and TB
 - > treatment of opportunistic infections
 - nutritional support
 - psychosocial support
 - > orphan care
 - legal support
 - > community and home-based care
 - treatment with ARVs
- The minimum package of antenatal and delivery care for all pregnant women in HIV-endemic areas should include:
 - provision of information on HIV/AIDS
 - ➤ VCT
 - nutrition support in pregnancy
 - STI syndromic management
 - ➤ additionally, for HIV-infected women the minimum package should include: appropriate management in labour, counselling on feeding options, ARV for PMTCT, ARV for the baby
- 3. Global guidance is needed on:
 - > packages of care and support, according to appropriateness and affordability in different settings
 - > use of prophylactic drugs for opportunistic infections in pregnancy
 - > support and care models for health workers and counsellors to prevent burn-out
- 4. Support outside the health facility: PMTCT programmes should link with support groups in the community for ongoing psychosocial support, home-based care and orphan care.
- 5. Postnatal services need to be strengthened.

DRUGS

The group formulated the following recommendations:

- 1. a check list for side effects of ARVs in mothers and babies should be developed and disseminated
- 2. WHO/AFRO needs to monitor development of resistant strains
- 3. more research needs to be carried out to determine the optimal dose of ARVs for babies
- 4. counselling of HIV-infected pregnant women needs to emphasize the importance of compliance
- 5. there is consensus that ARVs for PMTCT should be used only after HIV testing (no universal use of ARVs)
- 6. advocacy should continue to improve access to ARVs and regional alliances should be built for drug procurement
- 7. choice of drugs for PMTCT should be a country decision

SESSION 8: MONITORING AND EVALUATION

The session on monitoring and evaluation of the pilot projects included six sub-sessions:

- Country experiences (Cote d'Ivoire and Rwanda)
- Revised UNAIDS monitoring and evaluation document
- Overview on documenting experiences for Best Practices publications
- Overview of monitoring and evaluation
- Group work
- Examples of revised country plans (Tanzania and Zimbabwe) for monitoring and evaluation

Country Experiences

Cote d'Ivoire and Rwanda have gone through a process of reviewing the indicators discussed in the monitoring and evaluation meeting in Abidjan last year, and identified a common list to be utilised:

- ♦ ANC attendance
- iron/folic acid dispatched from pharmacy
- availability of tests
- pretest counselling
- post-test counselling
- seropositive tests
- return for results
- partners tested
- ♦ mothers receiving AZT
- infant feeding counselling
- family planning counselling
- use of family planning
- availability of ARV drugs
- episiotomy rate
- referral to social networks
- breastfed babies
- rate of infant morbidity and mortality during first two years
- number of infected babies at 15 months of age

The countries used various tools in the process of monitoring:

- ♦ ANC registers
- individual ANC consultation forms
- lab registers
- registers for HIV-infected women
- infant follow-up forms
- growth charts

The problems and challenges related to monitoring and evaluation in the countries discussed included:

- ♦ Difficulties in integration of MTCT monitoring activities into clinics' normal routine work because of under-staffing
- Need for good monitoring of data and quality supervision
- Need for good communication skills

Revised UNAIDS document on Local Monitoring and Evaluation

Isabelle de Vincenzi of UNAIDS presented the UNAIDS M&E document. She explained that there is a need for various levels of monitoring and evaluation in the pilot projects. These start with local monitoring, in each clinic, and should include continuous monitoring of coverage and quality of services. This can be done using data collected for clinical and administrative management for all clients.

In addition, there is need for a synthesis of local monitoring indicators, in the form of a process evaluation; and the measurement of outcome and key indicators, in the form of impact evaluation.

Core evaluation in each pilot project should consist of regular analysis of monitoring data, as well as data collected on a sub-sample of the population and enrolees. Extended evaluation will take place in some pilot sites. This will take the form of applied research, using data collected on specific samples, and responding to specific concerns.

The pilot projects include a cascade of interventions:

- introduction of primary HIV prevention activities and voluntary HIV counselling and testing services during antenatal care
- improvement of obstetrical care, including offering ARVs to HIV-infected pregnant women and adequate delivery practices
- infant feeding counselling during ANC
- post-partum care, including support to infant feeding, growth monitoring, family planning services and screening of HIV infection in children
- long-term support to HIV-infected mothers and their children

The objectives of the pilots will be specific to each country, but examples include:

General objective: reduce child mortality rates among children of HIV-infected mothers through the reduction of MTCT to less than 15%, and child mortality to less than 60 per 1,000 live births.

Specific objectives:

- provide ANC to at least 75% of pregnant women
- provide VCT to at least 75% of women seen at ANC clinics
- achieve compliance with ARVs of at least 75% among HIV-infected pregnant women attending ANC clinics
- provide safe delivery care to at least 75% of pregnant women
- provide infant feeding counselling to at least 75% of HIV-infected mothers
- ensure the use of IMCI services by at least 75% of children

The continuum of the intervention was described, in order to guide the selection of indicators for monitoring:

Primary HIV prevention & VCT	Obstetrical care	Post-partum child care	Mother & family care
Prenatal VCT	Anaemia prophylaxis	Infant feeding counselling	Counselling
Acceptance raising	Vitamin supplementation	Growth monitoring	Treatment of OIs
Condom distribution	ARV treatment	EPI	Palliative care
Routine STD diagnosis & treatment	Safe delivery	Micronutrient supplementation	ARV treatment
Support to share test result	Caesarian-section	IMCI	Family planning
Condom promotion among partners	Vaginal cleansing	Support of feeding practices	Acceptance raising in communities
VCT of partners	Avoidance of routine episiotomy	Distribution of BMS	Social support
Promotion of safe sexual behaviour	Avoidance of artificial rupture of membranes		Community support
Peer education & support	Voluntary abortion		Spiritual support

Of these various aspects of PMTCT, key interventions to be monitored should be selected on the following criteria:

- the intervention with the most impact
- the intervention that is the most problematic
- a new intervention we need to learn from
- the most expensive intervention
- interventions linked to other programmes for which we already collect data

Examples from the continuum of care that could be selected include:

Primary HIV prevention & VCT	Obstetrical care	Post-partum child care	Mother & family care
Prenatal VCT	Anaemia prophylaxis	IMCI	Treatment of OIs
Condom distribution	ARV treatment	Support of feeding practices	Family planning
Routine STD treatment	Avoidance of routine episiotomy		

Key implementation issues and questions to be considered include:

- Availability will the human and material resources necessary for the intervention be available?
- Access is the geographical and financial access satisfactory?
- Demand/utilisation do patients use the services?
- Continuity are the interventions used in a continuous way? Do patients adhere to the treatment?
- Quality are the interventions of good quality?
- Impact what is the impact of the intervention?
- Cost what are the costs of the intervention?
- Efficiency is the intervention provided in an efficient way?
- Financing what is the share of the various financing sources?

Guidelines to be used in choosing the dimension to monitor and evaluate for each tracer intervention:

- the importance of the given dimension for the overall effectiveness of the tracer intervention;
- the expected difficulties in the implementation of the tracer intervention (the most problematic intervention);
- dimension involving new activities we have to learn from;
- the possibility of identifying indicators easy to measure and providing reliable and interpretable information.

Examples of tracers in various areas are:

Tracer	Availability	Initial use	Continuity	Quality
Condom promotion	Availability of condoms			
STD treatment	Availability of STD drugs			
HIV counselling		Use of pre-test	Use of post-test	Quality of
		counselling	counselling	counselling
HIV testing	Availability of test kits	Use of testing		

Some indicators need to be measured for all the population in the pilot area, some for all pregnant women and some for all pregnant women depending on their HIV status, for example:

For all the population in the pilot area:

- availability of condoms
- availability of STD drugs
- use of family planning services

For all pregnant women:

- use of ANC
- > use of iron/folic acid supplements
- > availability of HIV test kits
- > use of pre-test counselling
- > use of HIV testing
- > partners tested for HIV
- > use of HIV post-test counselling services
- infant feeding counselling
- > family planning counselling
- ► HIV prevalence among pregnant women

For all HIV-infected women:

- > availability of ARV drugs in the MCH clinic
- initial use of ARVs
- continuity of ARV treatment
- receipt of ARV during labour
- episiotomy rate
- > exclusive breastfeeding at four months
- > family planning utilisation rate
- referral to a support network

For all HIV-uninfected women:

exclusive breastfeeding at four months

An example was given of how these indicators could be plotted for easy visual monitoring.

Monitoring and evaluation of HIV counselling is an area where extra effort is required, because it involves several dimensions:

- evaluation of political commitment to VCT, national laws and policies related to VCT
- operational evaluation/capacity to deliver the service (logistical considerations and linkages with support services)
- evaluation of selection of counsellors, training, support and "burnout"
- evaluation of counselling skills
- evaluation of counselling content
- evaluation of client satisfaction
- evaluation of attitudes to VCT in the general population
- cost-effectiveness

A proper evaluation of counselling will involve observations of client/provider interactions, and exit interviews with clients.

Another aspect to be monitored is costs and funding. The following is an example of a format for doing this:

Stages of production of effective coverage	Total Amount	Source of funding	Categories of additional costs
Cost of making resources			Cost of facilities upgrading
available			Cost of initial training
			Cost of additional personnel hired
Cost of ensuring access			Cost of transport for outreach
Cost of initial utilisation			Cost of condoms, STD drugs, ARVs, BMS, HIV and
			other lab tests
			Overtime of personnel
Cost of continuity			Cost of active tracking of defaulting women/partners
Cost of quality			Cost of technical training for standardisation
			Cost of regular refresher courses
			Cost of nutrition education

Several key items need to be measured in order to evaluate impact:

- > child infection status
- > infant and two-year mortality
- > negative life events for women following HIV testing and replacement feeding
- > positive life events following HIV testing
- > replacement feeding by HIV uninfected and untested women

This impact evaluation is not necessary on all women, but will be carried out by following-up a pre-determined number of mother-child pairs.

In some projects, special topics will be identified for extended evaluation. For these, special studies or follow-up on different samples will be required, or more detailed analysis of routine data:

- > successful referral for follow-up care
- > child growth
- > birth intervals
- > rates of exclusive breastfeeding among HIV-uninfected and untested women
- infant feeding methods by HIV-infected mothers
- ➤ HIV incidence among women initially HIV-uninfected
- > adherence to ARV treatment

Data collection methods and tools will vary depending on the final monitoring and evaluation plans of each country, but will involve:

- > modification of monitoring tools;
- > selection and careful follow-up of a sample of mother-child pairs (routine monitoring data plus additional information);
- > evaluation of VCT;
- > anonymous unlinked prevalence survey;
- rapid population-based survey (e.g., on fecundity, mortality, family planning coverage).

In the discussion following the presentation, the need for identifying good indicators for IEC interventions was identified.

Documenting Experiences for Best Practices

Bunmi Makinwa explained that the UNAIDS Best Practice collection endeavours to describe and illustrate good principles and examples of lessons learnt from the field. The rationale for Best Practices is that you do not have to reinvent the wheel, but rather can learn from others' experience in order to improve, and adapt lessons to your terrain and to make them work better.

For UNAIDS, Best Practice means accumulating and applying knowledge about what is working and not working in different situations and contexts. It consists of lessons learned, and the continuous process of learning, feedback, reflection and analysis (of what works, how, why, etc.)

The selection of a Best Practice is based on a simple description of accomplishments or on a thorough analysis using specific criteria.

The objectives of the Best Practice Collection are to:

- strengthen capacity to identify, document, exchange, promote, use and adapt Best Practice as lessons learned within a country and across countries, as a means to expand the national response to HIV/AIDS
- promote the application of the Best Practice process for policy and strategy definition and formulation
- collect, produce, disseminate and promote Best Practice

Best Practice strategies include:

- advocacy
- identification
- dissemination:

In identifying examples for Best Practice, there are three categories, with different review criteria:

- Exchange of experience:
 - documentation and production not required
 - > requires some form of dissemination
 - > may require some technical assistance
- Pilot testing and operations research:
 - documentation and production not required
 - > requires some form of dissemination
 - may require some technical assistance
- Documentation and production:
 - documentation and production required
 - physical dissemination required
 - may require some technical assistance

A review process is required if the UNAIDS stamp of approval is needed, which may involve global, regional or inter-country and/or country mechanisms, depending on the type of publication. If publication by UNAIDS is desired, a process that involves the UNAIDS Secretariat, field staff and co-sponsors may be involved.

Support and technical assistance is available in identification of Best Practices and drawing of lessons learned; in writing and documentation; in evaluation; and in various other aspects.

Practical Overview

As an introduction to the group work on monitoring and evaluation plans, a practical overview of monitoring and evaluation was given. We need to monitor and evaluate MTCT programmes in order to:

- 1. know what we are doing
- 2. know how we are doing compared to initially-set goals
- 3. identify where and how we should improve

Three areas should be considered for monitoring and evaluation. In order of priority:

- i. monitoring of coverage uptake (required for ALL patients approached in ANC settings)
- ii. medical and social impact (or programme effectiveness), that can be monitored for all MTCT clients if enough resources are available or, more commonly, on subsets of patients
- iii. basic evaluation

Monitoring of coverage uptake can include:

- No. of women attending ANC
- No. pre-test counselled
- No. HIV tested
- No. HIV-infected
- No. receiving AZT (No. of days, labour doses)

Medical and social impact, or programme effectiveness, can be measured through:

Focused quantitative assessments

Community support, stigma, feeding practices, growth monitoring, child morbidity and mortality

Selected samples

Transmission/infection rates in sub-samples

Evaluation should be based on programme objectives:

- ➤ ANC > 75% of childbearing women
- \triangleright VCT > 80% of women seen in ANC
- ➤ Provide >75% of HIV -infected women with an effective MTCT ARV regimen
- ➤ Reduce early transmission to <10-15%
- Final rate of <10-15% if replacement feeding

<20-25% if no replacement feeding

Monitoring tools (to support the M&E system) need to be in place, and can include:

Specific MTCT cards

One per patient, good link from mother to child, set aside to be entered daily

Extra burden for health care workers, duplicate information

Log books

Easy to use, kept on site, one line per patient

Difficult data entry (duration of follow-up), not practical if >2 service providers

Amended ANC and Under 5 cards

Easy integration within current health information system (HIS), good adherence, non-permanent changes

Risk of losing data when cards stay with mothers

Health centre supplies record

To record the information collected, a database must be created:

- choice: EpiInfo, Access, etc.
- immediate feedback and regular summaries
- can be interactive (clinic level)
- external support
- when choosing indicators, always think about data entry and analysis (avoid open-ended questions)

Some tips in designing a M&E system could include:

- keep it simple: stick to one-page rule
- integrate it within existing HIS
- keep only a few core indicators in the general system (15-20)
- subsamples can be used to answer operational research questions

Other important points to remember:

- design a unique identifier system (same number for mother and child)
- confidentiality
- duration of follow-up is a challenge
- timeliness for local feedback: one data manager per site
- flexibility for adaptation to evolving situation

A basic premise should be kept in mind when setting up the monitoring and evaluation system:

- we know the intervention works already (research settings)
- we want to know if we can make it work at the population level

The initial steps in setting up a M&E system include:

- Prepare list of key indicators
- Define collection methods for key indicators (questionnaires, surveys, existing HIS, new cards...)
- Amend existing health card or book (antenatal/paediatric) or create new monitoring
- Choose software to support database, create database
- > Train data manager
- Write data flow from patients' visits to data analysis
- Train health care workers about new monitoring
- Decide on variables needed for monthly summaries

Group Work

The group work had the following goals:

- Agree on a short list of key indicators
- Define collection methods (surveys, HIS, supply book, new cards...)
- Select a monitoring tool (book, cards...)
- Think about data base
- Identify areas where support is needed

Following the group work, two countries (Tanzania and Zimbabwe) presented examples of their revised monitoring and evaluation plans, which included:

Indicators for VCT:

- Proportion of women receiving pretest counselling for HIV
- Proportion of women tested for HIV
- Proportion of partners given counselling
- Proportion of women who are HIV -infected
- Post-test counselling
- Proportion of partners tested for HIV
- Proportion of clients coming for results

Indicators for infant feeding:

- > Proportion of women counselled on infant feeding
- Proportion of uninfected women practicing exclusive breastfeeding at four months
- Morbidity, mortality and malnutrition rates among children of HIV-infected women

Indicators for antiretroviral use:

- > Proportion of HIV-tested women who return for results
- Use of post-test counselling
- Continuity of ARV drugs
- Compliance to ARV

Indicators for post-natal care:

- Proportion who are HIV-uninfected
- Family planning utilisation rate

Indicators for safe delivery practices:

- episiotomy rate
- instrument delivery rate
- rate of artificial rupture of membranes
- > proportion of prolonged labour after rupture of membranes
- proportion of infected women given AZT during labour

During the discussion following the presentations, several issues were raised as problems and challenges:

- How to go about monitoring breastfeeding, including exclusive breastfeeding.
- The utilisation of staff in the monitoring of the activities is causing an increased workload. This situation is
 aggravated where home visits are required for follow-up. In some cases, there was already insufficient staff
 before the intervention.
- Good logistics for moving the data collected to the right place is important.
- Confidentiality needs more and new ideas, especially with regards to monitoring tools used in clinics.
- Insufficient financial support for various aspects of the intervention, particularly in monitoring and evaluation.

Session 9: The Way Forward

Experience on scaling-up

Brazil

Brazil has a population of 161 million and an HIV seroprevalence rate amongst adults of less than 1%. Of those 163,000 people currently infected with HIV, there are around 5000 children. The country has embarked on a nation-wide AIDS care programme that provides ARV triple therapy to about 75,000 patients through a network of 378 health units. These units can dispense ARV drugs which are centrally audited on a computer database and also monitor viral loads and CD4 counts. The success of the programme is evident by the reduction in incidence of opportunistic infections such as TB, *Pneumocystis carinii* pneumonia and other bacterial pneumonias, as well as a reduction in mortality. VCT centres are widely distributed and about 20% of the population have been tested (F: 26%, M: 15%)

PMTCT interventions:

ANC services extend to 80% of pregnant women and 90% of these women deliver in hospitals. 232 hospitals offer AZT (intravenous) at the onset of labour (the ACTG 076 regimen). Formula feeding is also supplied free of charge. In 1998, about 50% of eligible pregnant women received AZT.

In 1999 a national campaign to promote PMTCT was launched by the Minister of Health, using a combination of information folders for pregnant women and all doctors and media strategies including posters and television to increase awareness among the general public. This has resulted in increased acceptance of the programme.

Lessons learned:

- raising awareness about HIV and strengthening women's knowledge about the intervention has been crucial
 to the success of the programme
- uptake of VCT is high, due to unified messages and active promotion and support by all health workers, including doctors
- management of ARV therapy requires well-trained and motivated staff and an effective support system (laboratories, computers)
- large-scale VCT services cannot rely on health care workers alone; additional human resources need to be mobilised
- ARV provision is greatly facilitated by local production in Brazil of generic drugs, at a much lower price than commercially available ARVs
- emphasis on M&E, showing that the interventions work, has assisted to maintain commitment and mobilise resources
- main challenge is to improve the quality of antenatal care and counselling and to introduce cheaper testing technology (rapid tests)

Botswana

Dr. Mazhani, who presented earlier a recent review of the PMTCT programme in Botswana in the meeting, spoke about their plans for scaling up. The country is planning to move from pilots to a phased full national programme starting in July 2000, and hoping to cover the whole country by 2002.

Initial steps include:

- re-programming and strengthening of the implementation strategy
- strengthening of networking and partnerships
- > review of drug protocol
- the programme review has assisted in identifying constraints and proposing solutions

Lessons learned:

- aggressive IEC campaigns to create awareness are paramount to the success of the intervention; a larger communication strategy on HIV/AIDS which incorporates PMTCT needs to be in place;
- consensus building on policy issues is important before implementing PMTCT on a large-scale. Broad and specific objectives, as well as initial steps, should be agreed upon by all stakeholders.
- flexibility is needed to adapt the programme to local settings;
- political commitment has been maintained by the MTCT reference group informing the Permanent Secretary
 of developments on a monthly basis;
- VCT is, so far, based mainly at health-facilities and is an additional burden for health workers. Group pre-test counselling partially deals with the time constraints, but sites outside health units should also be opened.
- the MTCT reference group plays an important role in guiding the process and providing political accountability.

Discussion

- 1. How are districts selected for priority implementation?

 Selection is on the basis of a number of criteria, such as: seroprevalence, mix of urban and rural population, existing infrastructure, enthusiasm of health managers (difficult to measure!)
- 2. Why does the Botswana plan not make any reference to psychosocial support for mothers and children? These services are routinely organised for all HIV-infected persons and are reflected in the plan on counselling and psychosocial support. TB prophylaxis will be introduced in the near future as well.
- How is stigma and greater involvement of men addressed?
 These issues have been identified as major challenges and have to be addressed in the larger context of HIV/AIDS and not only within PMTCT. Partnerships with NGOs, churches and civil society are essential.

International Partnership against AIDS (IPAA) in Africa

Hilde Basstanie of UNAIDS Pretoria explained the IPAA:

- 1. Why a partnership now?
- AIDS in Africa:
 - is now the number one killer
 - has affected personally one out of four Africans
 - > is wiping out development gains achieved over the last decades
 - > is becoming the major threat to Africa's social and economic development
- Actions taken or not taken now and over the next few years to fight AIDS will determine the future of the
 continent.
- Need for a rapid expansion of the current response to AIDS to catch up with the growth of the epidemic. Current response and funding is grossly inadequate.
- We know what works and have seen some successes at local and country level through:
 - > public recognition of the AIDS problem
 - > commitment of national resources which attracts external funding
 - > a multisectoral approach
 - > involvement of civil society
- Political momentum: African leaders are breaking the deadly silence surrounding AIDS and speaking up.
- 2. What is the vision of the IPAA?

Within the next decade African nations will be implementing larger-scale, sustained and more effective national responses to HIV and AIDS. Through collaborative efforts and promotion and protection of human rights, countries will substantially reduce new HIV infections, provide a continuum of care for those infected and affected by HIV/AIDS, and mobilise communities, NGOs, the private sector, and individuals to counteract the negative effects of the HIV/AIDS epidemic in Africa.

- 3. What are the principles of the partnership?
- African political leadership
- Action centered at country level based on community identified priorities
- Respect for human rights and full involvement of people living with HIV/AIDS
- No new bureaucracy! We will build on existing global, regional and national structures

- 4. Who are the partners?
- UNAIDS Co-sponsors

Annapolis Resolution, January 1999

• African governments and their regional bodies

OAU Resolution, July 1999

Economic Commission for Africa resolution, May 1999

- Bilateral development agencies
 - London meeting, April 1999
- NGOs, including religious organisations

Consultations in Dakar, Lusaka, Gaborone (Aug-Sept 1999)

- Private sector
- 5. What are the main lines of action?
- Political mobilisation and advocacy: to generate broad commitment by engaging heads of state, regional bodies, local officials and influential leaders in religious, community, and business circles.
- Goals and strategy development: to provide a global framework for action, including clear goals and monitoring indicators on impact, local level partnerships, and technical and financial support.
- Country support: to assist in the completion and implementation of nationally negotiated joint plans of action with partners from various sectors and incorporating community-established priorities.
- Financial resources: to increase and redirect existing funds and mobilise additional resources from non-traditional sources.
- Strengthening technical resources: to support countries to access appropriate assistance in a timely fashion, build capacity, and improve the quality of interventions.
- 6. What has been achieved to date?
- Commitment from African governments and their Pan-African bodies
 - > OAU Resolution, July 1999
 - > OAU-UNAIDS agreement, September 1999
 - Economic Commission for Africa resolution, May 1999
 - > AIDS theme for African Development Forum 2000, African Ministers of Health meeting, August 1999
 - ➤ ADB, SADC, ECOWAS developing AIDS strategies
 - > face-to-face contacts with a large number of heads of state
- Advocacy materials developed: advocacy guide, leaflets, IPAA website, repackaging of IPAA information being done.
- Meetings of five constituencies:
 - Donor Group: London meeting, April 1999,
 - NGOs: Dakar (Aug.1999), Lusaka, Gaborone (Sept.1999)
 - Private sector: AIDS leadership meetings, hosted by Hillary Clinton (Seattle, Sept.1999) and the Gates Foundation (Jan.2000)
 - Programme Coordinating Board UNAIDS (May 1999)
 - Economic and Social Council resolution (July 1999)
 - Meeting convened by the UN Secretary General (Dec. 1999) with all five constituencies together
 - Security Council meeting (Jan 2000)
- Advocacy in country following Country Programme Advisers (CPAs) briefing, Jan 1999
- Partnership missions (Ghana, Burkina Faso, Tanzania, Namibia)
- Subregional meetings with CPA, Theme Groups, NAP (Maputo, Nairobi, Abidjan)
- Theme Groups expanding
- Agreement to intensify support in six countries in first six months of 2000, six other countries will be proposed for the second half of 2000:
 - ➤ Key functions, entry points and mechanisms for intensification developed: analysis of national strategic plans, generic steps for country intensification, partnership agreements at country level, support to countries for organisation of roundtables
- African Governments increasingly allocate own resources (e.g. Botswana, Namibia, Ghana, Nigeria)
- Bilateral development agencies are committing additional resources (US, Sweden, Canada, Netherlands, Norway)
- UN cosponsors have increased and reallocated resources; links with HIPC and Social Funds are being developed (Debt-for-AIDS initiative)
- Private sector involvement increasing: e.g. Bristol-Myers Squibb, Chevron Oil Company, Eskom, Rio Tinto

Upcoming events

XIIIth International Conference on AIDS, Durban, 7-14 July 2000

James McIntyre explained that the International Conference on AIDS will take place in Durban, South Africa from 7 to 14 July 2000. It is the first time that the conference has been organised in Africa. Compared to previous conferences, the programme strikes a better balance between scientific and community needs and will focus more on implementation problems in developing countries. The theme of the conference, "Break the Silence" refers to the silence of communities and individuals which obstructs acceptance and disclosure of HIV status as well as the silence surrounding global inequity in access to treatment and care.

- The scientific programme is organised in 5 tracks:
 - > (A) Basic science
 - > (B) Clinical science
 - (C) Epidemiology, prevention and public health
 - > (D) Social science
 - (E) Rights, politics, commitment and action
- The community programme consists of a two-day community forum, symposia, skills building sessions and debates
- PMTCT is well covered, in oral abstracts, satellite meetings, a debate session and round table sessions. Some highlights:
 - > Satellite meeting on breastfeeding and HIV: 7 July, 8:00 17:00
 - Scientific Track C05: Reducing MTCT: 10 July, 16:30 18:00
 - Debate session: HIV-infected women should be encouraged to exclusively breastfeed, 11 July 13:00 14:30
 - ➤ Scientific Track B08: Mother to child transmission, 11 July 14:45 16:15
 - ➤ Round table : MTCT: obstacles to implementation: 11 July, 16:30 18:00
 - ➤ Scientific Track C12: breastfeeding transmission of HIV, 12 July 13:00 14:30
 - > Satellite meeting on PMTCT pilot projects: 12 July, 18:00 20:30
 - ➤ Round table: International support for the prevention of MTCT: 13 July 14:45 16:15

Infant feeding training course, Harare, 3-7 April 2000

Felicity Savage King of WHO announced the UNICEF/WHO "Counselling Course on HIV and Infant Feeding" will be launched in Harare from 3-7 April 2000. See above.

Summary of issues raised and recommendations made during the meeting

Eric Mercier of UNICEF New York reminded the meeting of the context in which the pilot projects are being implemented. Each year, 600,000 infants are infected with HIV. The pilot projects were started in 1998 in a response to this. PMTCT is a high priority for UNICEF. The pilots started small, but scaling up has already begun.

While each country has set its specific goals for PMTCT, general ones seem appropriate:

- ➤ ANC services should cover at least 75% of child-bearing age women
- > VCT services should reach at least 80% of women who attend ANC
- > Over 75% of HIV-infected women should be provided with an effected ARV regimen to prevent MTCT
- ➤ Early transmission of HIV should be reduced to less than about 10-15%
- The final rate of transmission should remain at less than about 10-15% where there is replacement feeding, or less than about 20-25% where babies are breastfed

At the global level, a workplan and budget for PMTCT is being finalised by the Inter-Agency Task Team (IATT). The workplan includes support to accelerate implementation of the pilot projects, and to prepare for scaling up. A global meeting on PMTCT is scheduled for early 2001. The goals of the meeting will be to support implementation at national level and to mobilise resources.

From the deliberations in this meeting, it is clear that action in several areas will be necessary to support the pilots and begin the scaling up process.

- Expand rapidly access to VCT
 - Make rapid tests available
 - Expand counselling capacity by developing alternative models

- Document lessons learned
- Ensure networking between countries
- Ensure political commitment/create demand for VCT/PMTCT at the country level
 - > Support development and implementation of a communication strategy
 - > Develop prototype advocacy materials for policy-makers
 - Ensure networking between countries
 - Provide Best Practices on stigma reduction
- Clearer advice and support on infant feeding options to HIV-infected mothers
 - Enforce the International Code of Marketing of BMS
 - Reinforce the Baby Friendly Hospital Initiative
 - Provide full information to HIV-infected mothers on infant feeding options and support her choice
 - Research on critical issues related to HIV and breastfeeding needs to start now
 - Promote exclusive breastfeeding in light of the results of the 1999 Durban study
 - Develop policy and guidelines on breastfeeding at country level
- Monitoring and evaluation
 - Support country level monitoring efforts, particularly during the initial phase
 - > Improve the capacity to monitor the interventions at facility level
 - Support simple monitoring of the scaling up phase in order to learn lessons on how to expand
- Care and support
 - Ensure that in each site HIV-infected mothers and children have access to the best available care (including prophylaxis for opportunistic infections), and are referred to social services and local NGO networks
- Supplies
 - Improve the reliability of the provision of drugs, test kits and BMS
 - Forecast the quantity of supply for the next two years
 - Negotiate for the best prices of commodities

Needs for support

The country representatives met separately in one Anglophone and one Francophone group to summarise the needs for support. The purpose of the session was to agree on what support is needed to maintain the services in the pilots and gradually expand to other/all parts of each country over a three-year period.

Representatives from the regional and global level proposed, on the basis of the group work and discussions over the previous days, how the global and regional levels could optimise their response to the needs of the countries.

Country groups

Anglophone countries: this group identified the following needs for support:

- Human resources: support with training for health workers and community, including appropriate manuals and funding.
- 2) Regional guidelines and recommendations from WHO on:
 - drugs/ clarification on use of NVP
 - type of tests to be used (simple/rapid) as screening and confirmatory test, including recommendations on minimal level of qualifications of personnel performing tests
 - > infant feeding policies
 - prophylaxis for opportunistic infections
- 3) Support for development of communication strategy to facilitate:
 - advocacy for strong political commitment and resource allocation
 - > increased awareness in the community and increased demand for PMTCT interventions
- 4) Regional co-operation for:
 - > procurement of drugs and test kits (bulk purchasing via SADC, COMESA)
 - > registration of drugs
 - regional monitoring of drug resistance (WHO)
 - > co-operation in provision of care and support for mother and child

Francophone countries: this group added that support is needed for:

- 1) Training:
 - develop a training strategy at national level to expand training rapidly and include all health staff
 - > training for infant feeding counselling
- 2) Strengthening care and support for mothers and children
- 3) Ensuring the availability and quality control of tests, drugs and breast milk substitutes

Regional group

The need for a regional working group (RWG) of UN agencies on PMTCT was discussed in the PMTCT meeting in Abidjan (May 1999) and at ICASA in Lusaka (September 1999). The objective of the RWG is to coordinate the support to countries in planning and implementing PMTCT interventions and in going to scale. UNICEF is the lead agency in PMTCT in the region and UNAIDS will continue to be the secretariat of the RWG.

- The RWG will meet bi-annually, preferably during meetings such as this one. The focal points will link with the regional office(s) of their agencies and brief them on matters related to PMTCT.
- The RWG will continue to organise meetings to exchange experiences and lessons learned by countries. The next meeting will be for countries that are starting PMTCT activities, e.g. Central African Republic, Ethiopia, Eritrea, Malawi and Namibia.
- The RWG will compile a regional PMTCT work-plan, based on the work-plans of the agencies and the recommendations of the Gaborone meeting.
- A database of tools, documents, guidelines and modules will be compiled and made available to countries. A
 database of consultants will also be compiled.
- Partnerships with other organisations active or interested in becoming involved in PMTCT in the region will be formed, in order to expand the resource base and to ensure coordination of support to countries (e.g. CDC, Horizons, USAID, ITSF, ANRS, MSF)

Global group

This group consisted of representatives of the headquarters of UNICEF, UNFPA, UNAIDS and WHO (all members of the IATT).

First, the vision of the IATT was discussed:

- All UN agencies have identified PMTCT as a priority intervention. There is strong commitment towards PMTCT activities, and the will exists to allocate the necessary resources.
- The MTCT prevention package is based on a three-pronged strategy:
 - > primary prevention of HIV among parents-to-be
 - > prevention of unwanted pregnancies
 - > prevention of transmission from HIV-infected women to their offspring
- Recently, the IPAA was launched. All IATT partners support the integration of the PMTCT package into a broader HIV/AIDS strategy (including prevention, treatment and care, strengthening of health systems, and strengthening health information systems and surveillance).

Secondly, support to individual countries was discussed:

- IATT partners strongly adhere to the principle of channelling their support to individual countries through their national MTCT working groups. The IATT therefore encourages individual countries to strengthen and formalise these national MTCT working groups.
- IATT partners encourage the countries to move from pilot projects towards national MTCT programmes.
- IATT is also looking forward to expanding its activities into new countries.
- Finally, the IATT partners will feed back the recommendations of the six working groups to the respective inter-agency working groups. The ultimate objective is to respond better to the needs expressed by the individual countries during this workshop.

SESSION 10: SUMMARY OF CONCLUSIONS AND RECOMMENDATIONS

The meeting agreed that goals for the PMTCT initiative should be set in the near future. Participants also agreed on the following recommendations.

GENERAL

Countries should be supported in accelerating implementation of PMTCT programmes.

- 1. Countries that have been in the process of planning for PMTCT for the last one to two years should start implementation of the programme now. For those countries that have started, there is an urgent need to move beyond pilots to national, phased scaling-up.
- Participation in the planning and implementation of PMTCT programmes should be broadened to increase community support for HIV-infected women, and encourage stronger involvement of males and PLWHAs.
- 3. All cadres of health workers should be involved in the planning, implementation and monitoring of PMTCT programmes in order to influence acceptance of the intervention and enhance motivation.
- 4. PMTCT should be approached holistically, with the specific aim of integrating all elements of the programme into routine health services.
- Senior level political commitment is needed, and governments should also commit resources to agencyassisted efforts.
- 6. The initial planning and implementation of PMTCT programmes has identified several additional research priorities:
 - monitoring resistance to NVP and other ARVs used in PMTCT and their long-term implications
 - the application of new testing technologies and therapies
 - acceptance of different models of counselling interventions
 - feasibility of various infant feeding options in local settings
 - continuing research on use of ARVs to prevent post-natal transmission of HIV in infants
- 7. Many innovative approaches (e.g. to VCT) are being developed, and countries should be given opportunities to evaluate, document and share their experiences. This process should be supported through provision of inter-country technical support, field visits, joint training and networking within sub-regions.

INFANT FEEDING

Clearer advice and support of feeding options should be given to HIV-infected women.

- 8. National programmes, with the support of UN co-sponsors under the coordination of UNAIDS and in collaboration with other partners, should ensure that:
 - training on infant feeding for all health workers who care for mothers and babies, including PMTCT counsellors, is strengthened and accelerated. Training should include breastfeeding counselling, complementary feeding, infant feeding in PMTCT, and replacement feeding options.
 - breastfeeding specialists are more actively involved in training for infant feeding as part of PMTCT
 - the community and PLWHAs are included in the development of infant feeding policies and guidelines
 - messages are consistent between related programmes (e.g. IMCI, BFHI, SMI)
 - counselling on infant feeding and PMTCT is designed to enable the mother, in consultation with the health worker, to decide on the infant feeding option most feasible for her and best for her infant. The aim of the counselling should not just be to give information, but to empower the mother to assess the appropriateness of the alternatives in her specific situation.

COMMUNICATION

Programmes should ensure political commitment and create demand for VCT/PMTCT at the community level.

- Countries' capacities to develop and implement appropriate communication strategies on PMTCT will be strengthened.
- 10. Advocacy at all levels should be stepped up, with the focus on PMTCT as a human rights issue.
- 11. Best practices on stigma reduction should be developed and disseminated.
- 12. Inter-personal communication skills training packages for district staff should be identified and reviewed.
- 13. Special efforts should be made to achieve male involvement.
- 14. MTCT communication interventions should be integrated within the overall HIV/AIDS communication programme, with primary prevention efforts continued and strengthened.

VCT

Access to VCT should be expanded rapidly.

- 15. VCT is part of the comprehensive care and prevention strategy for women who test either positive or negative. Active links with other counselling services outside ANC testing, as well as services for TB, STIs and IMCI, should be developed to ensure that women, their partners and families have access to follow-up counselling and care where needed.
- 16. The counselling component of VCT is often seen as time consuming, adding to already heavy workloads, difficult and emotionally draining. There are many ways of sharing the counselling load, ensuring that counsellors are supported and the quality of counselling guaranteed:
 - Broader recruitment of counsellors to include PLWHAs, lay and volunteer counsellors
 - More appropriate training in basic counselling skills
 - Training follow-up focussing on skills for managing adjustment and difficulties following breaking bad news
 - Better professional support for counsellors' roles
 - Supervision to ensure higher and maintained counselling quality
 - Community referral networks for ongoing counselling and psychosocial support of those adjusting to HIV
 - Shorter pre-test counselling/no pre-test counselling where appropriate and where information from other sources is adequate
 - Exploring counselling models complementary to human resource availability

TESTING

Efforts should be made to streamline testing and to maintain quality control.

- 17. Given the increasing evidence and good experiences with rapid tests, countries should be encouraged to integrate them into testing algorithms in order to increase uptake of PMTCT programmes.
- 18. Clear guidelines should be provided regarding:
 - availability and appropriateness of testing kits for different HIV strains and prevalence rates
 - · quality control
 - training of health workers to enable disseminated use of rapid tests at primary health facilities
 - algorithm for diagnosis of HIV infection in young children
- 19. There should be regional coordination on:
 - procurement of kits, i.e. negotiating costs;
 - monitoring of resistance.
- 20. Quality control must be maintained.

ARVs

Countries need continual guidance in the provision of ARVs for PMTCT.

- 21. The use of ARVs for PMTCT should be based on knowledge of the woman's HIV status.
- There should be continued advocacy at global, regional and country level for access, affordability and availability of ARV drugs for PMTCT.
- 23. WHO should clarify its recent statement on NVP to give countries better guidance on its use.

CARE AND SUPPORT

Countries should ensure that in PMTCT programmes, HIV-infected mothers have access to the best available care.

- 24. PMTCT programmes should be seen as an entry point for a continuum of care. This would include access to condoms, screening for STIs, prophylaxis and/or treatment of STIs, tuberculosis and other opportunistic infections.
- 25. PMTCT programmes should promote establishment of linkages for care and support of orphans.

SUPPLIES

Reliability of the provision of drugs, test kits and breast-milk substitutes should be improved.

- 26. Forecasts should be made of the quantities of supplies required for the next two years.
- 27. Best prices should be negotiated for commodities.

MONITORING AND EVALUATION

PMTCT implementation needs to be monitored and documented so that lessons can be learned and experiences shared to ensure more effective scaling up. While governments have the primary obligation to monitor their programmes, UN agencies also have a responsibility for adequate funding and technical support during the development and early implementation phase. Specifically, agencies can support governments to:

- 27. Design simple and practical monitoring plans, compatible with available human resources in the health facilities. These plans should mainly cover the monitoring of programme uptake and could leave impact and extended evaluation for focused assessments.
- 28. Improve the capacity to monitor the interventions at facility level.
- 29. Support country manpower and logistical needs in order to implement these simple monitoring plans.
- 30. Support simple monitoring of the scaling-up phase in order to learn lessons on how to expand.

SESSION 11: CLOSING

Hilde Basstanie of UNAIDS closed the workshop on behalf of the UN agencies involved in PMTCT: UNICEF, WHO, UNFPA and the UNAIDS Secretariat. In brief,

- Participants were thanked for their commitment and hard work during the past 5 days; Ms Basstanie commented how impressed she had been by the excellent quality of presentations, the active contributions to discussions and the willingness of all participants to share their experiences with others. She commented that through these joint efforts the objectives for the workshop were achieved.
- Facilitators, resource persons, chairs and rapporteurs were thanked for sharing their expertise, guiding discussions and facilitating exchange and keeping records
- The government of Botswana was acknowledged and thanked for hosting the workshop and allowing participants to visit the pilot projects and learn from first hand observation and discussion with implementers
- Support staff from the Botswana team were lauded for the excellent logistical arrangements
- Ms Basstanie hoped that lessons learned during this workshop will assist countries to improve implementation and facilitate expansion of pilots and going to scale. She promised that the African Regional Working Group on MTCT will act upon recommendations and expressed needs for support and to integrate them into the joint UN regional workplan on MTCT. She trusted that the representatives of the Global Interagency Task Team will communicate recommendations to respective headquarters and follow them up.

- On a personal note, Ms Basstanie noted how fortunate she had felt to have had the opportunity during the week to get to know a remarkable woman. Florence Ngobeni, is working as a counsellor in the Perinatal HIV Research Unit in Baragwanath Hospital, Soweto, South Africa. Florence is living positively with HIV in the most inspiring way and continues to remind us that our efforts to reduce MTCT are very much needed, wanted and appreciated by the pregnant women we serve.
- Ms Basstanie stated that she felt honoured to introduce Florence Ngobeni to say the final closing words.

Florence Ngobeni:

"HIV/AIDS affect all of us and we need to work together to bring change in peoples lives. We need to change the way we talk to each other and also respect those who are infected. It will also help us as well if we start involving more PWA's in our programs because they deserve to be given another chance even if we know that they may die. Being invited to the meeting made me realise how much UNAIDS and its cosponsors care for the people living with HIV/AIDS. The prevention of mother to child transmission is a special program and I will make sure that I work together with other people to prevent more babies from dying. I thank everybody including Peggy Henderson, Hilde Basstanie for working so hard to bring people together and have a chance to learn and form a link and start working together in changing today's world." Florence then asked everybody to stand up and say the following: "I am special, and special people makes a difference". Florence then played music from a local band and everybody danced.

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ANNEX 2: Summary of Interventions in Pilot Projects – March 2000

Table 1: Summary of core interventions selected by countries as part of the MTCT pilot project

Interventions	BOTSWANA	Honduras	COTE d'Ivoire	KENYA	RWANDA	UGANDA	TANZANIA	ZAMBIA	ZIMBABWE
Community Mobilization									
IEC activities	Y	Y		Y		Y	Y	Y	
Voluntary Counselling and Testing									
Clinic based education sessions	Y	~	Y	Y		•	✓	✓	✓
Pretest group counselling	~			V		✓	V	V	· /
Pretest individual counselling	~	~	V	V		V	V	V	V
Pretest couple counselling	~			V			V	V	V
Post-test individual counselling	~	· /	✓	V		✓	V	V	· /
Post-test couple counselling	~			V			V	V	V
Post-test peer counselling	~						V		
ELISA HIV testing (+/- WB)	~	Y	· ·	~			V		
Rapid HIV testing	~		~	✓		~	'	~	

Interventions	BOTSWANA	HONDURAS	COTE d'Ivoire	KENYA	RWANDA	UGANDA	TANZANIA	ZAMBIA	ZIMBABWE
Short course antiretroviral regimen									
AZT (4-week pregnancy + labour)	Y *Starting 32/52 + treatment to infant	Y	Y	Y		Y + 1 wk for infant	Y	Y	Y
AZT + 3TC (pregnancy + labour + 1 week postpartum mother +/- baby)									
AZT + 3TC (labour + 1 week Postpartum mother + baby)									
Nevirapine								Y	
Provision of multivitamins to mothers									
Antenatal	✓	Y		Y		✓	✓	~	✓
Postnatal				Y		~	Y		
Obstetric measures									
Avoidance of artificial rupturing of membranes	~	Y		Y		V	~	V	V
Restricted use of episiotomy	V	Y		Y		~	~	~	~
Vaginal cleansing	~			Y			~	~	

Interventions	BOTSWANA	Honduras	COTE d'Ivoire	KENYA	RWANDA	UGANDA	TANZANIA	ZAMBIA	ZIMBABWE
Infant feeding									
Counselling on infant feeding	~	~	✓	Y		✓	✓	✓	✓
Implementation of baby friendly practices	~	~	✓	Y			✓	~	✓
Support of optimal technique of breast-feeding, if chosen.	~	~	V	Y		Y	V	~	~
Support of good technique of artificial feeding, if chosen.	~	~	~	Y		~	V	~	~
Provision of breast milk substitutes	· /	· /	✓	V		V	✓	~	V
Growth + development monitoring of child (monthly)	~	V	~	Y			~	~	~
Testing of baby									
Early PCR	See protocol		Y					Y (cohort)	
ELISA (15 months)	✓ (18mths)	· /	Y			~	V	~	/
Family Planning									
Provision of information and services for other methods	•	Y	~	Y		•	•	•	~
Counselling	V	Y	✓	Y		V	V	~	V
Provision of male condoms	✓	Y		Y			✓	~	~
Provision of female condoms	?						V	~	V

Interventions	BOTSWANA	HONDURAS	COTE d'Ivoire	KENYA	RWANDA	UGANDA	TANZANIA	ZAMBIA	ZIMBABWE
Psycho-social support									
Income generating activities							✓	Y	
Continued public education + Counselling	V	Y		Y		~	V	~	~
Outreach support services		V	Y			V	V	Y	

Table 2. Interventions for HIV negative women and women of unknown status

Interventions	BOTSWANA	HONDURAS	COTE d'Ivoire	KENYA	RWANDA	UGANDA	TANZANIA	ZAMBIA	ZIMBABWE
Voluntary Counselling and Testing									
Individual post-test counselling for women who have tested negative	Y	Y	Y	Y		Y	Y	Y	Y
Post-test counselling for women and their partner who have tested negative	Y			Y			Y	Y	Y
Infant feeding									
Implementation of baby friendly practices to support breastfeeding	~	Y	Y	•		•	•	~	~
Breast-feeding counselling and support of optimal breastfeeding techniques	~	~	V	~		~	~	~	~
Family Planning									
Counselling	✓	✓	✓	✓		✓	✓	✓	✓
Provision of male condoms	✓	Y		/			V	V	· /
Provision of female condoms							V	Y	Y
Provision of information and services for other methods	~	Y	V	~		Y	V	Y	Y